

“YOU JUST KNOW IT WHEN YOU FEEL IT”: A PARTICIPATORY INQUIRY
EXPLORING INCLUSION

by

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A Dissertation
Submitted to the
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of
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Dedication

I dedicate this dissertation to the Everyday Friends Research group, Ann, Lara, Mary, Rikki, Sophia, Teddy, Veronica, and Yahya, whose stories and passion fueled the work and made it possible for more voices to be included in research and knowledge sharing. And to Joey Roney and the Roney family, for teaching me the true spirit of inclusion and belonging through high expectations and steadfast loyalty and love.

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List of Abbreviations

| | |
|---|-------|
| American Association on Intellectual and Developmental Disabilities | AAIDD |
| Comprehensive Transition Program | CTP |
| Everyday Friends Research Group | EFR |
| Free and Appropriate Public Education | FAPE |
| Higher Education Opportunity Act | HEOA |
| Individualized Education Program | IEP |
| Intellectual and Developmental Disabilities | IDD |
| Inclusive Postsecondary Education Program | IPSE |
| Least Restrictive Environment | LRE |
| Participatory Action Research | PAR |
| Postsecondary Education Program | PSE |
| Primary Investigator | PI |
| Universal Design for Learning | UDL |

Abstract

“YOU JUST KNOW IT WHEN YOU FEEL IT”: A PARTICIPATORY INQUIRY EXPLORING INCLUSION

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George Mason University, 2022

Dissertation Director: Dr. Grace L. Francis

This research study explored the concept of inclusion at the postsecondary education program (PSE) setting through the perspectives of individuals with intellectual and developmental disabilities (IDD) through a qualitative inquiry. Specifically, this study focused on defining inclusive experiences and making recommendations for increased inclusion of individuals with IDD in college settings. The study used qualitative methodology through a collaborative and participatory design to understand inclusion from the perspectives of eight individuals with IDD who participated in a PSE program. Through qualitative conversations and thematic data analyses, the research group developed six key themes to support the definition of inclusion as well as three recommendations for choice to increase inclusive experiences at college. Last, this study included a critical self-inquiry in response to research procedures. This response provided a reflection on the efforts made to confront the traditional research cycle to increase inclusive practices within research alongside individuals with IDD, and reflected on

challenges related to power dynamics, acquiescence, and ableism. Implications for practice and future research are reported.

Keywords: intellectual and developmental disability (IDD), postsecondary education program (PSE), inclusion, participatory

Introduction

At present, there are approximately 6.5 million individuals with intellectual and developmental disabilities in the United States (Institute on Disability, 2018). Individuals with intellectual and developmental disabilities (IDD) are defined as individuals with disabilities with significant limitations in both intellectual functioning and adaptive behavior which originate before the age of 22 (American Association on Intellectual and Developmental Disabilities [AAIDD], 2021). Social inclusion and participation are now explicit goals of legislation, policies, and services for individuals with IDD across the globe (Grigal & Hart, 2010; Officer & Groce, 2009; Slee, 2019). Inclusion is a challenging concept to define and, as such, a variety of definitions or conceptualizations are used by stakeholders (e.g., policy makers, educators, advocates, families) in the disability community (e.g., physical placement in a school, an attitude towards acceptance of others; AAIDD, 2020; Keefe & Davis, 1998). This dissertation uses a joint position statement provided by two of the largest and historically representative disability rights organizations, the American Association on Intellectual and Developmental Disabilities and The Arc of the United States, to conceptualize inclusion of people with IDD:

People with disabilities should be welcomed and included in all aspects of society. Children should participate in the same activities as children without

disabilities. Children should learn in their neighborhood school in a general education classroom that contains children of the same age without disabilities. Adults should have relationships of their own choosing with individuals in the community. Adults should live in a home where and with whom they choose. Adults should engage in meaningful work in an inclusive setting and enjoy the same activities that are available to general public. (AAIDD, 2020)

The concept of inclusion evolved in this country over the last 60 years, primarily fueled by social and civil rights movements leading to federal legislation, and the fight for equal opportunity continues. Inclusion assumes there are power structures—defined for the purposes of this manuscript as United States society and government, and the educational system including academia—which allow or prevent inclusion. Labeling individuals with IDD as early as the birth of this country has paved the way for taxonomies of diagnoses and support systems, but has also determined (often preemptively) the level of participation or inclusion these individuals have been offered. In fact, not until 1973, nearly 200 years after the birth of our nation, did federal legislation specifically include the IDD population in the Rehabilitation Act of 1973. Following the passage of this momentous legislation, social, community, and academic inclusion movements continued (e.g., Americans with Disabilities Act, 1990; Education for All Handicapped Children Act, 1975; *Olmstead v. L.C.*, 1999).

Stakeholders continue to press the boundaries of inclusion in educational settings beyond the walls of K-12 settings, into communities, and in spaces of higher education including postsecondary education programs (PSEs), which are nondegree higher

education programs specifically designed for students with IDD. Until recently, educational opportunities for students with IDD ended when they left the public school setting as legal requirements for the Least Restrictive Environment (LRE) did not follow students into young adulthood as they transitioned from classroom to community.

To date, much of the research on PSEs documents positive postschool outcomes such as academic gains and employment opportunities for individuals with IDD (Grigal et al., 2018; Martin & Williams-Diehm, 2013) as well as descriptive research outlining factors attributed to successful program PSE development (Grigal et al., 2014). However, research on these positive outcomes due to PSE inclusive experiences is lacking (Prohn, 2014). Further, research focused on PSE opportunities for individuals with IDD has consistently left out the individual with IDD, and instead gathers input from other stakeholders (e.g., staff, professionals, parents, general education students). This is not, however, unique to postsecondary education research and individuals with IDD. Individuals with IDD have historically been prevented from participating in research and knowledge construction as valued participants, and instead have either been ignored entirely, exploited or forced to participate without proper consent, or used as subjects. At this time, more than ever before, there is opportunity to instill change and shift the disability and special education research paradigm to be more inclusive of who is participating in creating new knowledge.

There is a promising, albeit small, body of research on successfully including individuals with IDD as research participants or co-researchers. For example, in a scoping review Walte et al. (2017) outlined 11 studies that included the voices of students

with IDD and concluded that including individuals with IDD in research is feasible as long as accommodations and modifications are considered and provided to participants. Few studies focused on PSEs have sought to include individuals with IDD as participants—not subjects—in research aimed at understanding—not “fixing”—perspectives and experiences. A participatory action research (PAR) study was conducted by Paiewonsky (2011) and aimed to document college experience of students with IDD enrolled in a PSE. This study identified six themes about college to share with other students interested in attending: (a) having a new identity and feeling different, (b) access to different classes, (c) adjusting to new expectations, (d) working with educational coaches, (e) campus life, and (f) transportation.

Building on Paiewonsky’s work, a 2014 doctoral dissertation by Prohn investigated social inclusion from the perspectives of students with and without IDD at a PSE level. This study found that the definition of social inclusion was not similar between students with IDD and peer supports without IDD. Francis et al. (2020) conducted a qualitative phenomenological study aimed at investigating the experiences related to interactions between family and PSE professionals from the perspective of the student with IDD. This study included only individuals with IDD and through use of thoughtful semi-structured protocols the researchers were able to conduct trustworthy qualitative interviews that were accessible to participants (Francis et al., 2020). Findings from all three of these studies reinforce the need for more research at the PSE level which includes the student as the participant, as the students are the primary stakeholders.

This dissertation was developed based on the following key conceptualizations: (a) individuals with IDD have historically been marginalized and left out of society, educational opportunities, and research; (b) despite social movements and federal mandates, inclusion continues to vary in definition across settings, resulting in the continued exclusion of individuals with IDD; (c) Comprehensive Transition Programs (CTPs) have attempted to create and define Inclusive Postsecondary Education Program (IPSE) settings with limited input from students with IDD; (d) though extremely limited, research indicates that purposeful inclusion of individuals with IDD in research is not only responsible, but can yield valuable information; and (e) individuals with IDD have been systematically and systemically left out of the research process. Therefore, the significance of this work is the addition to the fields of special education and disability studies as well as qualitative methods by investigating the concept of inclusion from the perspective of those individuals who have lived it.

This research study followed a qualitative participatory inquiry approach alongside young adults with IDD who attended a PSE program, and their experiences with inclusive settings. Manuscripts one and two present the findings of qualitative participatory inquiry exploring inclusion at PSEs from the perspectives of individuals with IDD. Manuscript three presents a self-reflection position paper on confrontations of the traditional research cycle, and considerations of power imbalance, equity, and ableism.

You Just Know It When You Feel It: Expert Perspectives on Inclusion

Abstract

Inclusion continues to be widely discussed and debated as a setting, program, or ideology as it relates to individuals with intellectual and developmental disabilities (IDD) in educational settings including postsecondary education programs (PSEs). As PSEs continue to increase in popularity and availability for individuals with IDD, inclusion remains a key benefit. Research documents inclusion at PSEs as it relates to program structure or postprogram outcomes, yet leaves out the perspective of students and individuals with IDD who experienced inclusion. Individuals with IDD have the expertise and experience which should inform PSEs and educational spaces on best practices for inclusion. This study investigated the experiences and perspectives of inclusion from eight adults with IDD who participated in a PSE. Through qualitative conversations and analysis, six key themes emerged to further understand the concept of inclusion at the college setting. Implications for practice and future research are reported.

Keywords: intellectual and developmental disability (IDD), postsecondary education program (PSE), inclusion, experiences

Inclusion is a fixture in educational settings as it is linked to numerous benefits including increased learning expectations and social skills among all students (Kurth & Mastergeorge, 2010; Kurth et al., 2015). Research documents the positive impact of inclusion on students with extensive support needs, including students with intellectual and developmental disabilities (IDD), or individuals with significant limitations in both intellectual functioning and adaptive behavior originating before age 22 (AAIDD, 2020). Such positive outcomes include: (a) improved academic outcomes (Agran et al., 2014; Browder et al., 2008), (b) increased social skills (Boutot & Bryant, 2005; Carter et al., 2015), and (c) increased self-determination skills (Wehmeyer et al., 2013). Likewise, research documents the positive impact of inclusion on students with IDD enrolled in postsecondary education programs (PSEs), nondegree higher education programs specifically designed for students with IDD. Since the passage of the Higher Education Opportunity Act (HEOA, 2008), efforts to improve transition outcomes and increase inclusive PSE access for students with IDD continue to grow (Weir et al., 2013). Documented outcomes related to these inclusive programs include increased vocational skills and employment opportunities (Grigal et al., 2014; Plotner & Marshall, 2015), academic enrichment and course access (Agarwal et al., 2021) and increased inclusive social opportunities (Qian et al., 2018). A relatively new higher education initiative, interest in PSEs continues to grow, necessitating the documentation of PSEs' successes and challenges to inform program development and reform. Gathering the perspectives of the key stakeholder, the student with IDD, is essential to support the conceptualization of inclusion, a foundational component of all PSEs.

Inclusion in Education Policies

Inclusion policies now recognized in K-12 and postsecondary settings originated from landmark litigation known as the Education for All Handicapped Children Act of 1975 revolutionized “inclusion” among students with IDD through the provision of a “free and appropriate public education” (FAPE) in a student’s “least restrictive environment” (LRE), which mandates that “to the maximum extent appropriate, students with disabilities will be educated in instructional settings as close to that of nondisabled peers with supplementary aids and tools necessary to succeed” (this legislation is now known as the Individuals With Disabilities Education Improvement Act [IDEA], 2004). These mandates paved the way for students with IDD—a population historically educated in segregated settings—to learn alongside their peers without disabilities. Through FAPE in a student’s LRE, students with disabilities may learn in a fully inclusive environment alongside peers without disabilities 100% of the time, or 0% of the time, depending on the extent to which the student’s Individualized Education Program (IEP) team determines is “appropriate” for the student.

Ambiguity regarding what is “least restrictive” (e.g., the extent to which a student is in an “inclusive” environment)—while purposeful to support individual student needs—has prevented an explicit definition on inclusion, inclusive education, or systematic guidelines to determine LRE. As a result, an LRE determination largely rests on expectations, experiences, and advocacy efforts of IEP team members. This often leads to students with more extensive support needs such as students with IDD experiencing education in segregated settings (Kurth et al., 2014; McCabe et al., 2020).

While LRE regulations do not occur in higher education, a PSE’s comprehensive transition program designation under HEOA (2008) guides inclusive program requirements. Students who attend a PSE with a comprehensive transition program designation spend at least 50% of their time (as reported by PSE administration) in one of the following settings: (a) enrollment in college courses with students without disabilities, (b) auditing college courses with general education peers, (c) enrollment in noncredit or nondegree courses with general education peers, or (d) internships or work-based training with nondisabled individuals (HEOA, 2008). In short, “inclusion” (implicitly stated or otherwise) for students in primary, secondary, and postsecondary settings addresses inclusion through ratios: a percentage of time students with IDD learn in settings among students without disabilities on a scale of 0% to 100% via LRE, or spending a minimum 50% of time among individuals without disabilities in a PSE with a comprehensive transition program designation. What is unclear, however, is how inclusion is experienced.

The perspectives of PSE students and graduates—individuals with firsthand expertise with “inclusion” in the K-12 and higher education settings—are best suited to inform and shape the field of PSE programs and disability research. Expertise in an area of life (e.g., inclusion at college settings) develops through tacit knowledge acquisition (Collins, 2018). Specifically, the perspectives of PSE students hold unique knowledge and experiences (e.g., attending elementary, secondary, and postsecondary education settings; having a disability; attending a PSE; experiencing situations defined by others as “inclusive”) and, as a result, are critical in attempting to understand inclusion in

postsecondary settings. Research on inclusion which includes individuals with IDD, however, is limited and not always conducted in the U.S. context (Abbot & McConkey, 2006; Hall, 2009; St. John et al., 2018). With social and academic movements focused on enhancing inclusion, then, it should be expected that this population be included in the research, if not co-constructing new ideas for programming, as individuals with IDD are the ones most knowledgeable and impacted by inclusive research, policy, and programs.

As a result, the purpose of this paper was to investigate experiences of inclusion at PSEs held by young adults with IDD who attended a PSE through reflections on the question “What is inclusion?”

Methods

This qualitative study followed a participatory inquiry approach and borrowed from phenomenology (Creswell, 2013; Merriam & Tisdell, 2016) and narrative inquiry (Clandinin & Connelly, 2000; Merriam & Tisdell, 2016). Additionally, the following onto-epistemological beliefs guided this work: (a) research can be inclusive when the needs—including impairments—of participants are acknowledged and supported (Walmsley et al., 2017), (b) lived experiences result in expertise (Collins, 2018) and story sharing leads to knowledge production (O’Grady et al., 2018, Reissman, 2008), and (c) the ethic of humility acknowledges the primary investigator (PI) needed participants more than the participants needed the research (Limes-Taylor Henderson & Esposito, 2019). Therefore, group member commitments (participant goals and choosing how to participate) were important for this study aimed at accessible and meaningful participation.

Participants

Prior to this research, the PI had existing relationships with all potential participants through local community groups including Special Olympics and Best Buddies. Recruitment flyers were sent to a Special Olympics email distribution list and posted on the PI's social media page. Interested individuals contacted the PI directly via email indicating they wanted to participate.

Purposeful selection (Patton, 2015) was employed and participants were selected if they met the following criteria: (a) were an individual with IDD, (b) graduated from a PSE, (c) expressed an interest in participating in the research study, (d) could independently access video conferencing tools such as Zoom, (e) had access to technology (e.g., smartphone, tablet, laptop), and (f) agreed to participate in individual and focus group interviews. Zoom was chosen for the following reasons: (a) free access for all users during the pandemic; (b) potential participants' reported knowledge and prior use of the platform; and (c) the availability for audio, video, captioning, video recording, and transcript generation.

In total, eight individuals participated in the study as co-researchers. The PI obtained consent from participants via an IRB-approved consent form which included modified language (e.g., simplified sentences, familiar terminology) and visual aids (e.g., thumbs up and green check marks to indicate approval, thumbs down and red "x" to indicate nonapproval). Two of the eight members were their own guardians and provided consent forms directly to the PI. The other six members provided assent through forms,

and were required to obtain guardian consent as well (e.g., a parent or guardian reviewed the study procedures and approved participation via electronic signature).

These co-researchers named the research group Everyday Friends Research (EFR). EFR co-researchers included both females ($n = 6$) and males ($n = 2$) and ages ranged from 21 to 32 years. Seven of the eight members attended the same four-year PSE program where they participated in self-contained specialized courses (referred to as “PSE courses”), participated in job training, attended university general education courses (not earning credit, referred to as “university courses”), earned certificates of program completion, and had the option to live on campus. Five of these seven PSE program students lived on campus for at least one year during their college experience. The eighth co-researcher attended a two-year PSE program at a community college. Table 1 displays additional EFR member demographics.

Table 1*Everyday Friends Research Group Participant Demographic Information*

| Name | Age | Gender | Disability | Own Guardian | Ethnicity | Current Residence | Currently Employed |
|----------|-----|--------|-------------------------|--------------|----------------|-------------------------------------|--------------------|
| Sophia | 26 | Female | Autism | Yes | White | Home with family | Y |
| Rikki | 22 | Female | Seizure disorder | No | White | Home with family (NP) | N |
| Teddy | 22 | Male | Not shared | No | White | Community with chosen roommates (P) | Y |
| Veronica | 24 | Female | Down syndrome | No | White | Community with chosen roommates (P) | Y |
| Lara | 29 | Female | Intellectual disability | Yes | Not shared | Home with family (NP) | Y |
| Mary | 32 | Female | Intellectual disability | No | White | Home with family (NP) | Y |
| Ann | 27 | Female | Not shared | No | Asian | Home with family (P) | N |
| Yahya | 25 | Male | Down syndrome | No | Middle Eastern | Home with family (NP) | N ^a |

Note. Some names are pseudonyms as chosen by Everyday Friends Research (EFR) members. Information was provided by members and/or guardians and confirmed by co-researchers during interviews. Place of residence was reported at time of interviews. P indicates “preferred setting” and NP indicates “nonpreferred” as reported by participants. ^aLaid off due to COVID-19.

Data Collection

Data collection and analysis took place simultaneously and iteratively throughout the study. Iterative data procedures allow for continuous reflection and adjusting of study direction as well as inform future data collection and analysis (Merriam, 1998). Due to

the COVID-19 health pandemic and increased social distancing measures, this study was conducted virtually in accordance with university IRB procedures over the course of seven months. Study procedures emerged from the participatory design expectation that participants are active co-researchers involved in each step of the research process (Fals Borda & Rahman, 1991; Fine & Torre, 2004; Kemmis & McTaggart, 2007). As such, data were collected in multiple ways including semi-structured interviews, group interviews and discussions, and adapted Photovoice interviews with different team members leading discussion and analysis procedures. The EFR group met on Monday evenings between 6:00 pm and 8:00 pm, as this was a preferred time for all members. Though protocols were developed and utilized by the PI, discussion topics were also informed by group meetings and the natural direction of conversation. For example, while a protocol was focused primarily on inclusive experiences or memories, EFR members became excited talking about their recommendations for prospective college students, and, as such, the conversation shifted to brainstorming and ideas for future discussions.

During Weeks 1 and 2, the purpose of meeting in a group and one-on-one was to establish and build rapport between the PI and EFR members through group discussions, icebreakers, and individual interviews. Though all had a preexisting relationship with the PI, meeting in a research group setting was unfamiliar, and these initial weeks allowed the PI to introduce and/or reteach key concepts and vocabulary (e.g., research procedures, distinguishing between an interview and a conversation, explicitly defining “inclusion” as it would be used throughout the study). Additionally, these weeks provided immediate

feedback for the direction of the study. For example, during the Week 2 group discussion, EFR members suggested creating a running agenda with live notes to be displayed and added to during conversations.

The first round of individual interviews took place during Week 3. Additionally, EFR members shared individual goals for the research group during the weekly group discussion. Semi-structured interview protocols were used in each individual interview, and all EFR members answered the same questions during the interview.

During Weeks 4 through 6, the EFR group met three times as a group, and reflected on individual interviews and inclusive experiences. This was also the beginning of EFR members leading group meetings, and group analysis procedures. To aid in this process, the PI provided modeling and facilitated conversations when needed.

Additionally, the EFR group developed a word cloud visual (a cluster of words depicted in different sizes depending on the frequency used) during Week 5 in response to the discussion prompt “Inclusion is....”

Week 7 served as a check-in week. In addition to the weekly group meeting, individual conversations and check-ins were conducted to gather feedback on the direction of the study and members’ feelings about participation. The PI and EFR members discussed analysis and next steps (e.g., developing main ideas from the noted patterns in conversation) and the PI continued to share examples of analysis completed thus far. This check-in week also resulted in a noted shift in study direction, as many EFR members shared goals of developing recommendations for future students attending college as well as recommendations for PSE staff.

As a result, Weeks 8 and 9 focused on discussion surrounding recommendations for inclusion, as well as EFR member-led discussions. This led to discussions of hopes, dreams, and future plans which were the primary topics throughout Weeks 10 and 11. During Week 11 group meetings included sharing visual data, and engaging in visual data analysis. The final three weeks of meetings included individual interviews and group meetings focused on reviewing analysis and finalizing themes as a group. During Weeks 13 and 14 EFR members shared their interest in continuing to meet and/or sharing the work at a future time. Two EFR members indicated interest in continuing to meet in the future.

Individual Interviews

Individual interviews took place throughout the study. Each co-researcher participated in at least two individual interviews to establish rapport, build relationships, and participate in visual analysis. Individual interviews lasted between 20 minutes to an hour, and served as a touchstone for individuals to check in with the PI, speak or share freely, and to discuss protocol questions centered on inclusive experiences across settings in college, current or future goals for work, living, relationships, and feelings about the research process. Co-researchers who preferred group discussions participated in two individual interviews (Weeks 1 or 2, and Week 7), and those who preferred one-on-one conversations participated in up to four individual interviews (Weeks 1 or 2, Week 4-6, Week 7, and Weeks 11-13). PI-developed interview protocols (Appendix) were used in each interview session. These protocols utilized concrete and concise language, which was adapted based on prior protocol and discussion tools used with individuals with IDD

in the PSE setting such as rating (good, better, best, most to least) and story sharing (“Tell us a story about a time when”; Francis et al., 2020), and was kept flexible (e.g., questions could be skipped, repeated, or new topics allowed for conversations to continue) to allow for participants to share stories beyond the scope of the questions.

Adapted Photovoice Interview

Participatory photographic research methods support individuals engaging in research who may require visual support or prefer to communicate other than through spoken word. Photovoice is one participatory approach to data collection and analysis procedures which can support amplification of historically marginalized populations (Wang & Burris, 1997). This approach is used to visually record and honor the voices, experiences, and knowledge of individuals and issues impacting their lives (Call-Cummings et al., 2019). The use of Photovoice with individuals with IDD has been proven an effective way to collect data and increase participation of individuals in the research process (Cheak-Zamora et al., 2018; Jurkowski, 2008; Povee et al., 2014; Prohn, 2014). Typically, Photovoice encourages participants to take photos, assign caption© to the images, and share photos as part of analysis procedures (Wang, 2006).

In light of the COVID-19 pandemic and social distancing measures, our visual support procedures instead invited EFR members to locate a personal picture that reminded them of or represented inclusion in their lives. Additionally, co-researchers were also offered the option to draw “inclusion.” Five of the eight co-researchers shared photographs as part of the interview process. This adapted Photovoice interview drew from Wang’s (1999) SHOWeD process to discuss the visual data source (see Appendix

for SHOWeD Process). The SHOWeD Process is designed to facilitate participants. However, the PI adapted the SHOWeD process to support team members in more robustly articulating their individual experiences and to encourage discussion among the EFR (Francis et al., 2020).

Adapted Photovoice Analysis

As EFR members shared a chosen photo on the screens, the PI led a discussion with the following protocol questions: (a) what do we **See** here, (b) what was **Happening** on this day or in the background of this photo, (c) why is this image **Important** for Inclusion and/or what makes you think of inclusion when you see it?, (d) what are your **Memories** of this day, and (e) what can this photo **Teach** people about inclusion? After each question, EFR members provided answers and additional details about the image shared. This protocol, while used as an interview technique, also served as an analysis tool when discussing inclusion and experiences depicted in the visual data described in greater detail below.

Group Interviews

Group interviews and discussions also served as a primary data source, as well as for analyses procedures. In order to develop a safe group environment, the research group met initially to practice group discussion dynamics through Zoom (e.g., muting, sharing screen, raising hand and use of emojis, the chatbox function). Group interviews initially followed a semi-structured protocol with open-ended questions developed by the PI (see Appendix). Meetings began with general rapport building through greetings and welcomes and an icebreaker (e.g., Share your favorite movie, best meal in the last week)

followed by versions of conversation prompts related to inclusion, college experiences, and favorite memories (e.g., what was your favorite event on campus, who remembers the campus movie theater, did anyone ever feel left out?). All members were invited to lead group discussions and develop individual research questions to lead conversations. Individuals who indicated interest (verbally or via email or text with the PI) chose a future date to lead. Interested EFR co-researchers took turns leading group meetings and prepared discussion topics and research questions to pose to the group. EFR members were not trained in qualitative research, and as such, the PI encouraged them to approach leading as they would any discussion with friends or colleagues. Specifically, the PI encouraged members to “make this meaningful” for them, and talk about what matters to them. Additionally, the PI provided facilitator support as needed (e.g., screen sharing, rewording questions, or supporting the co-researcher in calling on members to share answers). Figure 1 shows an example of an EFR member-created protocol.

to: [REDACTED]

my question for next monday will be

1 does anyone have some ideas and suggestions? of what kind of inclusion projects we could work on with the group

2 i would love to hear some stories from the past when you first started school in middle school and high school

3 what kind of fun activities did you do when you used to be a student on campus at [REDACTED] but now we are [REDACTED] alumni to you all vist the campus and social events at [REDACTED]

4 What classes did you audit off campus at [REDACTED] and did you talk to the program manager in the [REDACTED] program. and lastly what kind of magazines and newspapers and newsletters could we use for are inclusion group

[REDACTED]
Note. An email with a proposed list of questions to guide the research group conversation.

Figure 1

Team Member-Developed Research Question Protocol

Data Analysis

Data analysis was an iterative process and began immediately once data collection started. During all interviews, the PI kept a running record of field notes and preliminary jottings (Saldana, 2016) in a researcher notebook with significant pieces of information noted next to the time of recording for further analysis and member checking as necessary. Influenced by Collin's (1992) conceptualization of a holistic research process, as well as recommendations for inclusive analysis from Tilley et al. (2021), data analysis, like data collection and study design, remained fluid, and dependent on EFR member input (e.g., sharing about future hopes and dreams in addition to college memories) as well as transparent (e.g., co-researchers knew their stories would be reviewed and analyzed).

Preliminary Analysis

The PI engaged in preliminary analysis “behind closed doors” and was not participatory, as the PI engaged in this process without direct participation from other EFR members. During this analysis stage, recordings were transcribed using Zoom software and Rev.com and the PI read transcripts while listening to recordings to clean and de-identify transcripts, ensured transcription accuracy, became familiar with the data, and noted emerging themes (Creswell & Poth, 2018). The preliminary analysis team consisted of the PI and one faculty member with expertise in the field of special education and disability research who was familiar with the design of the study and served as the chair for this dissertation. Use of open coding and thematic analysis techniques often found in grounded theory analysis and narrative inquiry (Clandinin & Connelly, 2000; Strauss & Corbin, 1998) were used to identify and develop major themes or ideas emerging from perspectives of young adults with IDD. This analysis process was shared with EFR members during group analysis, and so the methodological decision to use plain language when describing each step was purposeful and important. For example, traditional thematic analyses methods follow procedures and use specific language (preliminary or open coding, in vivo codes, categories, themes, theory; Saldana, 2016). This process followed these same traditional steps explained as reviewing our meetings, listening for the same words and feelings, picking important parts of the story using the individual's words, putting it in your own words, and sharing why it is important to the group. Familiar and accessible language (e.g., listening for same words

instead of repetitive refrains) was used to ensure EFR members understood the process and could participate.

The decision to employ thematic analysis was important because it identifies themes based on a participant's specific or exact words (Riessman, 2008), remaining true to the commitments of inclusive, participant-as-expert research. To engage in thematic analysis, the PI performed open-stage coding in which codes are formed by reviewing participants' vocabulary, expressions, and input to develop potential categories for group discussion (e.g., emotions, places, people, situations). Next, the PI generated a list of interesting themes based on the categories from interview data which turned into overarching themes in group analysis. Primary analysis followed during the group work stage, where initial categories and themes were shared with EFR members.

Primary Group Analysis

Primary analysis was group-generated and participatory and took place during three group discussions and four individual discussions. The PI served as co-facilitator during these analysis meetings and modeled identifying repetitive words, emotions, categories (e.g., friends, happy, belonging) and themes heard throughout discussion as well as shared the preliminary interpretations gathered from the first analysis phase. For example, the PI read a portion of a transcript or replayed an audio excerpt of a conversation with a participant (with permission) and asked the group to share one or two ideas or phrases they heard throughout the recording. At the end of each shared excerpt, audio clip, or viewing of visual data, co-researchers would engage in analysis through one or more of the following steps: (a) share words or phrases that seemed important to

them, (b) agree or disagree with statements heard, (c) respond using the statement “this person is saying ___ is important,” and (d) this teaches us ___ about inclusion. Using group analysis procedures such as priority sorting (participants identify the top two or three points of significance from a story or shared experience), the group identified major themes.

Visual analysis using the adapted SHOWeD process protocol was also performed during the group analysis stage. For example, Sophia shared a photograph from the first time she met her Best Buddy and shared details of the story behind the image (Figure 2) through answering the protocol. As a team, EFR watched the recording of Sophia’s visual data interview and shared thoughts after hearing her discussion.



Caption:

PI: What do we see here?

Sophia: Me, with that other person is my peer buddy for the Best Buddy [Program Name]

PI: So what's happening here? What is the story behind the picture?

Sophia: Well, I mean that's my first day meeting her in person. After talking with her on facetime.

PI: Very nice! Exciting! Why is this picture important for inclusion?

Sophia: I just thought it was part of inclusion because this is inclusion to me. She's [pretty] nice.

PI: What are some things that make her nice?

Sophia: well she offered to pay for me [sic] lunch and ice cream

PI: Nice! Did you go to lunch or ice cream on that day this picture was taken?

Sophia: Yeah, we went [to get] lunch and ice cream after we took that picture.

PI: Yum! What other memories do you have about this picture or that day?

Sophia: Well that was a huge day for me, my first time getting to meet her. I had her meet my mom.

PI: I see. Is it important for you that your friends meet mom?

Sophia: Yes

PI: Why?

Sophia: Because it's so my family to know my friends

PI: That makes sense. What does this picture teach us?

Sophia: I think it teaches inclusion.

PI: Yeah? Tell me more about that. Why?

Sophia: Well the Best Buddies program likes to promoting [sic] inclusion as well. And I was happy with a new friend that day.

Note. This image chosen by Sophia represents inclusion and is described using visual analysis protocol.

Figure 2

Example Visual Data Provided by Everyday Friends Research Group (EFR) Member

In response to viewing and listening to Sophia's interview, EFR members' analysis included the following: (a) Inclusion is getting lunch with friends, (b) it feels good to have a friend "like a best buddy, someone you can trust" (Lara), (c) family is important and helps inclusion, and (d) inclusion is when people are nice.

Trustworthiness

Throughout all research activities, various forms of scaffolding were used to adapt and support co-researchers' understanding of and access to knowledge construction and data following guidelines from Universal Design for Learning (UDL; CAST, 2018) principals. UDL promotes three key strategies to increase access regardless of ability, which were used throughout the study. First, providing multiple means of representation such as large text in note taking, the use of visuals and captions during Zoom calls, preteaching inclusion and research-related vocabulary during initial interviews, and using simplified and accessible language throughout all research study procedures. Second, providing multiple means of engagement through offering/allowing choice in research topics and sessions, choice in data collection tools, personalizing interviews based on EFR member interests and needs (e.g., Teddy preferred to share less about disability label, Yahya was interested in focusing more on future plans, Veronica was interested in research activities, and Rikki preferred to listen and answer questions from protocols), and varying the social demands for interaction (e.g., allowing Sophia to participate in more 1:1 meetings instead of group discussions). The third strategy of promoting multiple means of action and expression was provided through allowing chatbox or email responses to verbal questions, promoting multiple media forms (e.g., photos, drawings

and sketches, and EFR member-generated interview questions), and modeling analysis procedures. Additional adaptations included: (a) use of subtitles in Zoom meetings, (b) enabling the chat feature for co-researchers to write responses, (c) providing protocol and discussion questions to co-researchers prior to meetings, and (d) individual follow-up conversations to support understanding and ensure accurate interpretation of co-researcher stories.

Research conducted with individuals with IDD often reports issues concerning acquiescence, or “yeah-saying”: indicating agreement with the researcher regardless of participants’ true feelings or beliefs (Hollomotz, 2018). To address this, the PI encouraged participants to share details about their experiences and perspectives through prompts such as “how did you feel then, how do you feel now, what was your favorite, what did you dislike, do you have other memories of this” and supported participants to express themselves in multiple ways (e.g., nonverbal, verbal expression, written expression, drawing). Moreover, the PI sought to create a sense of comradery and comfort in the EFR by reiterating the group was a research team made up of experts, all participation was welcome and voluntary, and the group allowed space and time for members to engage in discussion on all topics (e.g., not related to the research but instead socializing, catching up).

In addition, throughout all data collection and analysis activities and conversations, frequent and consistent member checking procedures were employed to ensure accurate interpretation of the data (Reed & Francis, 2021). Following discussion or a shared story, the PI would repeat back what was heard and ask if the phrase or

paraphrase was accurate. Additionally, the PI would ask the storyteller to repeat certain parts or sentences, and probe further asking them to “tell me a little more” about the topic. During group meetings, volunteers were invited to retell or summarize what a co-researcher had shared to support group understanding of the story.

Findings

The purpose of this study was to understand inclusion from the perspectives of young adults with IDD through collaborative and participatory inquiry. While the research question initially focused on inclusion at the postsecondary level, many of the discussions and stories included experiences from high school and life in general, as well as college. EFR members' participation and contribution throughout the study varied. For example, some members were consistently eager to share verbally as soon as a question or prompt was presented/asked (as noted by unmuting, raising a hand, starting to speak immediately, etc.), whereas others chose to utilize the chatbox to respond, or email their thoughts after the meeting had ended. Additionally, some members participated through acts of agreement (e.g., nodding, clapping, smiling, or Zoom emoji expressions) and disagreement (e.g., frowning, shaking heads, thumbs-down emoji, putting face in hands) without verbal expression. After three rounds of analysis, six major themes emerged to describe and define inclusion from the co-researchers' perspectives.

Theme 1: Inclusion is People > Places

EFR group members shared that memories of inclusion were tied to specific people and friends, regardless of place or setting. Being with people was important for them to feel inclusion: “I think to get together with groups and with my friends ” (Ann),

“making friends” (Sophia). When reflecting on inclusion, EFR members shared stories about being with friends, being part of a group, and feeling happy with friends. Rikki shared in-depth information which reflected the EFR group discussion surrounding how they spent their down time or nonclass time at college. The best part of the PSE was “meeting new friends” and she enjoyed being in a group of friends: “Like friends from [PSE] class say at lunch ‘Oh, do you want to sit with us?’ and I felt happy that I sat with them at lunch.” Rikki also specified that being in a group of people could sometimes be hard, but when the group was comprised of friends it felt easy: “Sometimes it’s hard and sometimes it’s easy to be in a group of friends, or just a group.... When you ask if you can be in a group and then they say yes, sometimes at lunch.” Rikki indicated that sitting with people at lunch was more important than sitting in a specific restaurant or location on campus.

The idea that inclusion means having a safe space also resonated across EFR members’ stories. Yahya shared that he felt most included when hanging out in his dorm. Teddy preferred the PSE building hallway where students from the PSE program were allowed to hang between classes and socialize; “I liked how the hallway was kind of like the area where we can chit-chat and be together.”

A number of stories involved feeling inclusion at school or work because of the people EFR members were with, but not specifically the setting. Mary shared that she felt included at work (an office off-campus) when socializing with her co-workers and when people talked to her: “One benefit that I really love the most is doing my work and talking to my co-workers, and to ask them what their weekend plans are.” Similarly,

Yahya shared that he felt inclusion while working, not because of the location of his place of work, but because he was able to be with people and socialize: “I was working [at department store] and it was amazing. I loved talking to people.” Teddy and Veronica described experiences in the university course classroom (university course with degree-seeking students) where other students in the course influenced their feelings of inclusion more than physically attending the course. “One of the [PSE program] students helped me in that class,” Veronica shared, and continued to describe the relationship between herself, a peer with a disability, and a new friend without a disability that developed in a university course: “So I met her [friend without disability] since she was taking the same class as me, which is amazing. So that’s how I got included.” Teddy shared an experience about being enrolled in a university course and feeling alone. When asked what would have improved that experience, he answered that having friends from the PSE program in the class would have helped: “It’s just hard if they [faculty] pick on you to say something, you’re like, ‘I don’t know nothing about this class I’m not learning it very well [when] I’m alone.’ But they don’t do that because they don’t want the people to get distracted [by friends from the PSE].”

Theme 2: Inclusion is Friends Who “Get Me:” People Like Me

In addition to the general belief that who was present was a greater factor in feeling inclusion over location, EFR group members described inclusion as being around friends who are similar to them, who have disabilities, and who understand their experiences. Rikki emphasized the importance of a friend group with disabilities because they understand what it is like to deal with medication or recover from a seizure. She

shared, “Yeah, I like [*sic*] hang out with people that might understand my disability.” Further, she relied on friends for support and trusted them when she was feeling tired (warning signs of seizure): “Yeah and I can tell [friend with disability] about the seizures and stuff and they usually help me take a break.”

Veronica shared that before coming to college she struggled with bullying, feeling isolated, and being the only one with a disability at her schools. Positive inclusion experiences and happy memories for Veronica included meeting others with disabilities and finding her community at college: “I was making friends that have a disability, which actually amazed me because I never thought I was making friends since I moved here for the first time.” Similarly, Yahya shared that the friends (with disabilities) he made during his college experience became family to him. When asked if it mattered to him to be with other students with disabilities while at college he shared, “ I love it...I see people that have disabilities, I see them as my friends, my buddies.” In particular, Yahya’s friendship with a person with a disability deeply informed his description of inclusion: “Yeah, we are very close because I see [friend] as my brother. Not a friend, he’s like a brother to me.... It's the best part of my life when he took me by the reins.” Ann shared her favorite memories of feeling inclusion took place when she went to Special Olympics, Best Buddies, and a theater class with other friends with disabilities: “I like [PSE-sponsored theater club] and Best Buddies and Special Olympics together with friends.” Ann shared these friends (with disabilities) were made during her time at the PSE and she now sees them on the weekend through Special Olympics events.

Defining inclusion as being around friends who are similar was especially important to EFR members when discussing socializing or “sitting around and hanging out” (Yahya), as well as sharing housing and living arrangements. In fact, Teddy described that he wanted to enroll in a PSE program on college campus to meet “a bunch of people who were also different” who also had disabilities. When sharing favorite memories and experiences, many members of EFR told stories about groups of friends heading to the movie theater, going out to eat, and hanging out after PSE courses. For example, Teddy shared that he felt inclusion when he spent time with friends from the PSE outside of class: “Some nights we would have karaoke and just chill in the [residential hall] lobby and play music and sing along.” Yahya’s stories of trips to the movie theater with friends from the program were filled with happy memories: “I remember [campus movie theater]. Oh my gosh, [reminiscent headshake] those days were amazing. I remember so many movies with [friends from PSE]. It was so much fun. I had so much fun.” Living with roommates who are similar were frequent topics of discussions and contributed to members’ experiences with inclusion. Mary shared that she and her roommates with disabilities specifically were looking for a third person with a disability to move in and live with them: “We were hoping to look for another roommate that have [*sic*] a disability”; Veronica also shared that she currently lived with three friends from her PSE, as well as Special Olympics. Teddy described friendships with two other individuals he lived with in the residential hall during college and that he planned to move in together off campus: “They’re just cool and are pretty awesome together. We lived together before [COVID-19]. It’s cool that we’re getting this opportunity that we

can just be together. I think it will last a long time.” He indicated that these friendships are so strong because they are so similar in their interests and daily living schedules and priorities: “We all like the same things, like doing the same stuff, playing basketball and being able to be outside, do stuff and can talk to each other. Also we can all drive and so yea, that's pretty cool.”

Theme 3: Inclusion is Choice

EFR members' stories and memories were seasoned with individual experiences of making choices about their lives, and therefore associated feelings of inclusion. Many members shared that they felt inclusion when they chose how to spend their time, where they went, and what they did. For some, the more choices they were allowed to make on their own, the more included they felt. Veronica shared, “I think it's because I am more independent, and I have been making new friends being included in Special Olympics, different meetings.” She added that it was important to have choices and options for different activities: “I was included with [PSE-sponsored] book club, and let's say go to basketball games and see friends instead of sitting in you [*sic*] dorm room.” While enrolled at the PSE, students were provided with options for spending time outside of class—some PSE-sponsored (for students in the program with disabilities) and others available to all college students while on campus (clubs, sporting events, concerts). Veronica really led this discussion, eliciting nods and agreement from EFR members, particularly Lara and Ann. It was important to her to have options to choose from, “You can go out with friends or maybe to the gym to exercise. There were several things going on at campus.”

EFR members also described how choice surrounding classes impacted their experience with inclusion. Mary shared that it is important to have a say in what classes to enroll in: “I felt included when I spoke up for myself and got to audit some [university] classes. I went ahead and I did it on my own and I loved those classes a lot.” Veronica added that it is important “to set goals for ourselves” in order to feel included. For example, Veronica was interested in theater and music, so she advocated to take (university) classes on theater and music.

Additionally, choice in roommates was important. Some EFR members shared that not being able to choose roommates (“It was more who could go with who,” Teddy) resulted in difficulty. Veronica shared that her first roommate was assigned (by PSE staff) to her without choice and she faced conflict, “I was being picked on by a former roommate.... I wasn’t feeling comfortable and they [roommate] wouldn’t let me go out and see my friends...it was not safe at all.” Similarly, other members shared that their dream living situation would be to live with chosen roommates in preferred places. For example, Mary shared, “I would love to live in a townhouse without my parents bothering me, where I could have freedom.” Ann shared, “I would love to live with my friends because I think it would be fun to be with friends.”

Additionally, feeling limited in daily life choices such as finances, leisure time, and friendships also negatively impacted how members experienced inclusion. Mary shared she wanted more freedom from rules and parenting to choose how she spends her time: “Getting the chance to have more time to myself and get some more inclusion [*sic*] to myself, so I can spend more time and enjoy my life.” Rikki shared that it was

important to choose where she ate and whom she sat with on campus, and that it was disappointing when those choices were not honored and she could not sit with preferred friends due to mandatory PSE schedules or PSE staff instructing her to branch out and meet other people: “I felt kind of disappointed and bad because they’re my closest friends.”

Theme 4: Inclusion is Opportunity and Permission

EFR members, including Lara, Veronica, Ann, and Sophia, described inclusion as having the opportunities and permission to join campus or local organizations, participate in activities, and attend events. For example, Ann shared,

One of the things I like[d] to do as a student was going to basketball games, I also did [PSE] book club which was fun and lots of activities. You know, Best Buddies [and Theater club] and Special Olympics practices.

Veronica added that her feelings of inclusion increased from her first year to her third and fourth years in college because more opportunities to participate were made available to her, “like since I started doing the [university] pep band, there you go...I was excited and included.” Similarly, Mary and Teddy felt more included as more opportunities offered to them by PSE staff: “So on my third year I started to intern at [Capitol Hill] and I got to work with [congressman and senator] which was a good opportunity” (Teddy), and “I was given opportunities to write articles about certain things and it got published in [school newspaper] and I was so happy” (Mary). Additionally, Lara’s positive experience with inclusion stemmed from her opportunities during internships and job placements facilitated by PSE staff: “I liked to work at my desk when working on the

projects with the co-workers, they are all very nice and sometimes we [did] schedule lunch dates.”

PSE staff providing or denying permission to participate in an organization, living arrangement, academic course, or leisure activity negatively contributed to EFR members’ experiences with inclusion. For Veronica, a powerful story surrounded her memories of peers and friends with disabilities being explicitly prevented from joining on-campus organizations by PSE staff or campus leadership—an experience she described as “definitely not inclusion:” “So they [PSE administration] weren’t allow [*sic*] any [PSE] students to join a sorority, fraternities, and they weren’t being able to join the student government. It was just really hard...it was a big struggle.” Conversely, Veronica shared that she was the only member of the [university pep band] with a disability and was given permission by the PSE leadership and pep band director to join which was important to her: “So that’s my inclusion, like since I started doing the band I got to study music, there you go, I got really excited.”

Theme 5: Inclusion is Support

EFR members shared that support was required to feel inclusion. For example, all EFR members shared stories of positive memories of college related to the support provided (e.g., staff members, PSE policies) in order to feel inclusion. Alternatively, experiences of needing support to feel included but not receiving it (e.g., bullying, relationship conflict, uncomfortable living arrangements, university course assignments) impacted feeling inclusion. At times, PSE program rules and staff members facilitated interactions between EFR members and others without disabilities. For instance, Teddy

shared that it was important for him that PSE staff support students to experience inclusion by “letting everybody have a chance to do something with everybody.” He also shared that one of his favorite memories of inclusion was a tailgating event:

We were with [PSE] staff that don’t have that disability and they [PSE staff] were just more friendly and helpful I would say...we were all just hanging out and the [PSE] staff were letting us do different things, introducing people and inviting them to our tailgate.

Support from PSE staff was particularly helpful to support inclusion in housing situations. Veronica and Mary shared that PSE and university residential hall staff support while at the university and a paid housing support staff in a house after graduation made living outside of the family home in the community easier. Veronica described wanting a former PSE staff member as a “housemate” because she was friendly and to provide support:

[make sure] I have money to get groceries because it’s important and also learning how to cook...a person like me, who has a disability and one person who is a mentor in the general population should work together to learn how to cook and maybe do laundry, independent living, which is important for inclusion.

Mary shared that while she preferred to live with others who have a disability like her, she is also more comfortable and feels included with formal support in place:

so when we [roommate and family members] decided for [name of matriculated student met at university] to move in as an RA [residential advisor], I actually felt

like it was great idea to get to know her and she can help us become more included in our community.

Mary shared that support in the form of a PSE staff (referred to as peer mentors) helped her feel included in a university course: “It was just me and the [university] students in the classroom but I had a mentor to help me understand so it helped me to feel confident and included in class.” Mary also shared, “I also got help from the [PSE] teachers and it helped me to speak up and voice my opinion and feel inclusion.” Rikki also discussed feeling excluded in certain university courses because she did not have support from a peer mentor, and that not understanding the material added to her feelings of isolation: “There were a couple [of courses] that are hard to just sit and listen and remember stuff because I was alone and didn’t have help.”

EFR members also shared it was important for inclusion to know there were planned, supported activities they could expect or anticipate each week. For example, Lara described weekly outings planned and facilitated by PSE staff and their help with accompanying PSE-program classmates to the bowling alley on Friday evenings.

Theme 6: Inclusion is that Feeling: You Just Know It

Like an intuition, EFR members shared that when they experienced inclusion they often could not tell you why. Simply put by Sophia, “I just know when I’m included. I know it when I feel it.” This refrain of “feeling inclusion” consistently emerged throughout conversations; the group returned to this notion of “feeling it” to determine if the experience was inclusion.

“Feeling inclusion” was particularly apparent during storytelling and visual analysis of EFR members’ personal photographs. Ann, Rikki, and Veronica all shared pictures of themselves with family and friends, and described knowing they are included when they are with these people. Ann explained “this is inclusion because we love each other” as she shared a photograph of herself and sister smiling and hugging. When sharing her picture Veronica said, “I’m with my family which is very good, because it’s how I can just be. Around. And they love me when I had a disability. They were happy I came to their world.” Similarly, Yahya shared he felt inclusion the most when he was with his family: “I know inclusion because I feel it with my sisters. I have a good relationship with my family.”

Ann also chose to share a photograph (Figure 3) taken on the day of her graduation ceremony along with related feelings and memories.



Note. Image of graduation ceremony described by Ann: “This is my graduation day I was very proud to be included at the [*sic*] ceremony.” She added: “inclusion is celebrating at graduating [*sic*] with everyone at the [event center]. I was feeling included at that graduation.”

Figure 3

College Graduation Ceremony Photograph Representing Inclusion

For some EFR members, inclusion was described as the absence of feeling bullied or left out. Rikki consistently returned to stories of feeling good with her friends. Ann shared that her inclusive experiences were when “Everyone is kind to me and there are no bullies just kind to me in college.” She added “inclusion means not being lonely and doing things together. I feel happy and comfortable when I am included.”

During a group analysis activity the EFR group created a word bubble (a collection of words or phrases that appear in a cluster or bubble, with word sizing representative of how many mentions the word or phrase was used) in response to the prompts “When do you feel inclusion” and “What does belonging and inclusion mean.” This exercise emerged from conversations where it became difficult to share a memory or

experience (e.g., extended periods of silence, responding with “I don’t know”). Each member provided words or phrases that came to mind when thinking of inclusion and belonging in order to create a visual word bubble. As EFR members contributed words, it became clear that inclusion was just as much of a feeling or intuitive knowing as it was a place or persons defined (Figure 4). “Happy, feeling like at home, hopeful, safe, good, exciting” were among some of the words and phrases shared.

WHEN do you feel INCLUSION?

Monday March 8



Note. Visual data word cloud generated by Everyday Friends Research group (EFR) words and phrases associated with “inclusion” used in analysis.

Figure 4

Word Cloud Representing Inclusion

Discussion

The purpose of this study was to understand what inclusion means to young adults with IDD who have participated in a PSE program. As PSE programs are increasingly marketed as inclusive (e.g., academic access to university courses; Becht et al., 2020); social access to organizations (Uditzky & Hughson, 2012), it is troublesome that students with IDD are not involved in research projects or program development dedicated to constructing the claims of inclusion (Prohn, 2014). This study emerged from a need to understand inclusion from the perspectives of young adults with IDD through an inclusive and collaborative research design. The goal of this work was to investigate a phenomena alongside individuals who have experienced it firsthand, and to strive towards participatory research methods.

EFR group members consistently shared that their memories and feelings of inclusion were tied to being with specific people, regardless of the place or setting. This is consistent with Abbot and McConkey's findings related to inclusion for young adults with IDD as well (2006), reinforcing the importance of understanding that the people, not the place, is what inclusion means.

PSEs across the country are actively seeking CTP status, the gold standard of inclusive college programs. Teddy's experience of being a student with IDD in a university course is a common example of "inclusion" (a method for meeting the 50% ratio of time), yet he describes feeling alone and left out without his chosen friends. Veronica's story also highlighted the importance of having a friend in the university course in order to feel included, not simply being in the physical class setting. These

experiences are not unlike the experiences of degree-seeking college students, where social networks and friendship positively impact academic success and mental health (Bronkema & Bowman, 2019; Schmidt, 2020).

As humans, we tend to gravitate towards those with whom we share culture or interests (Montoya et al., 2008). For young adults with IDD, this is not an exception. EFR group members shared that when they think of inclusion, they think of being in a group of friends and feeling that they belong. Particularly, EFR members shared that friendships made with those from the PSE who also identify as having disabilities contributed to feelings of inclusion.

There were very few conversations surrounding college and inclusion which did not also involve independence and choice. Like any young adult or college student moving away from home for the first time, there is freedom to make choices about how and where to spend time, and with whom to share it (including no one). EFR co-researchers consistently shared positive feelings of inclusion when choice was present (e.g., choice of classes, choice of roommates, choice of leisure activities). Similar to choice, the resounding conviction among the group was the more opportunities offered or permission granted, the more inclusion they felt. There was a distinction between opportunity (an option or the chance) and permission (a person controlling access or opportunity). However, these two constructs were often connected if not entwined. For example, without the permission of university faculty or staff, the opportunity to join or access a space could not exist. Alternatively, when EFR members found (through seeking out on their own or through being informed by a peer or PSE staff) an opportunity for

activity or a club, the permission to join was not inherently granted. Moreover, similar to Abbot and McConkey's (2006) study, individuals with IDD associate inclusion with being provided opportunities to participate in, attend, and be given access to events or activities. Choice and decision making indicate a level of agency, independence, and trust that is often not afforded to individuals with IDD (Bigby et al., 2019), impacts how they may access or participate in their schools, and supports the notion of ensuring access to disability-centric (Special Olympics, Best Buddies) as well as nondisability-specific (intramural sports, campus clubs) communities.

For many EFR members, simply being a student at the PSE was not an inclusive experience. When sharing positive experiences and memories of inclusion, every member of the group described an extracurricular organization or activity (Best Buddies, Special Olympics, PSE book club, university sporting events). It is important to note that many of the organizations mentioned by EFR members were designed specifically for individuals with IDD, and whether professionals and nondisabled stakeholders consider these organizations "inclusive," the fact remains that EFR members *choosing* to join such groups was tied to feeling inclusion. Further, the explicit naming and requesting for permission to be given is a critical, yet painstaking point of discussion. EFR members acknowledged—seemingly comfortably so—that they are at the "mercy" of those in power granting permission. Power dynamics between individuals with IDD and staff or support team members (family) without disabilities boldly presented themselves through these discussions of joining events or activities. Even throughout this study aimed at

understanding and achieving inclusion, such inclusion resulted from a person in power (the PI) requesting and allowing (creating space for) responses.

Participants agreed that feeling included required help; it did not always happen naturally regardless of the physical setting or specific people present. College is often considered a time to find independence and freedom, so it was illuminating to hear that while those things are important, EFR co-researchers appreciated and expected help and support as they transitioned to postsecondary settings. Simply arranging for a student with IDD to enroll or attend a university course does not ensure inclusion, despite the commonly held conviction that accessing general education settings or being with other people with disabilities in a nondisabled setting is inclusion (Slee, 2019). Help in the form of person-to-person support, preferably by same-age paid or unpaid peers, increased feelings of inclusion among EFR members. This is consistent with research linking help provided by unpaid or paid peer mentors without disabilities to higher levels of inclusion among individuals with disabilities across settings and contexts (e.g., academic settings; Brock & Huber, 2017; Lee & Taylor, 2021; employment or vocational settings; Carter et al., 2019). Similarly, the request of and appreciation for help within dorms and housing indicated that help increased feelings of inclusion. Additionally, this study highlighted the importance of receiving help from friends and peers *with* disabilities which added to feeling inclusion. Rikki's trust and reliance on her friends from the PSE was in part due to their shared experience of having a disability, and she depended on them for help.

EFR members' stories reflected that quantifying time spent (e.g., at least half of their time in a setting with students or individuals without disabilities; HEOA, 2008) or

labeling based on needs (e.g., least restrictive environment; IDEA, 2004) used to define and facilitate “inclusion” provided a framework aimed at equity, but missed the most humanizing aspect: how people feel.

A basic tenet of quality of life and well-being is belonging (Maslow, 1943; Schalock et al., 2010), and EFR member stories and conversations consistently related feeling inclusion to feeling that they belonged (in university classes, in friend groups, at activities, and within their families) and feeling safe (e.g., with people like them, in disability-centric spaces, with help/support). In the word cloud exercises, the feeling of inclusion was interchangeable with feeling belonging—both in definition and when providing examples of when members felt they belonged or felt inclusion. Additionally, all of these descriptions were associated with happiness and well-being, which help to make up the foundation of humanity (Kersh et al., 2013; Maslow, 1943). This warrants a critical consideration of when and how one “feels” inclusion that can only be informed by individuals with IDD.

Above all, these findings are important in showcasing the expert opinions regarding inclusion. Little research exists which centers the perspective of the young adult with IDD, and of those, proxies or secondary data sources are often included (e.g., family members, professionals, peers without disabilities) to “confirm” truths or reach an accepted level of trustworthiness. Providing space for sharing stories and experiences, listening to those, and then believing and accepting them as truth is important to acknowledge individuals with IDD as capable and valued experts who contribute to research.

Limitations

There are four primary limitations in this study. First, the relatively small research group of eight may be perceived as a limitation. Though the goal of qualitative research is not to generalize, including more participants may have allowed for additional stories which confirmed or enriched the EFR group perspectives on inclusion. Only eight individuals shared stories throughout this study, and more stories can increase understanding. Additionally, one of the eight individuals attended a different PSE. While participants were not disaggregated, and overall that person's experiences and contributions were similar, this may be seen as a limitation.

Second, of the eight co-researchers, only five elected to self-disclose a disability label, and documentation (e.g., IQ, adaptive scales, educational level based on standardized assessments) was not required for participation in the study. As a result, the PI did not confirm diagnoses among the EFR (although an IDD label is a requirement to attend a PSE), which may be a limitation and call into question if the right population is being represented.

Third, the lack of in-person meetings and required use of Zoom software for data collection and analysis due to COVID-19 may have impacted participant accessibility therefore the stories shared. Requiring use of the Zoom platform also required microphone and/or camera access, up-to-date technology, and reliable wireless connections. This likely also impacted the participant pool (e.g., those with the means to have an individual device once a week). Additionally, requiring Zoom presupposes a

certain level of ability and skill set (e.g., navigating a computer, communicating through spoken or written words).

Last, a common critique of participatory design with individuals with IDD includes challenges of power dynamics and significant limitations in just how “participatory” and “inclusive” the study is as it progresses (Nind & Vinha, 2014). The varying level of participation from each EFR member may be another perceived limitation, and in the future studies should address power dynamics and possible acquiescence (e.g., answering a certain way to please the PI or group members, or foregoing one's own opinion to agree with a statement; Furnham, 1986) taking place when conducting research with this population.

Implications for Practice

This study identified six primary themes related to feeling inclusion, with an emphasis on people, support, choice, and feelings. Inclusion was described as being with people (not places) and people similar to you (homogenous), which is inconsistent with the current focus on programmatic percentages (CTP), and K-12 (LRE) education placement decisions. The university course setting remains inclusive, but a major implication from this work is that inclusion requires positive interactions with relatable people. As a result, it is critical that individuals with IDD be at the forefront in designing their PSE experiences (where and how to spend time and with whom). Co-creating disability-oriented “safe” (Teddy) spaces can increase feelings of belonging and inclusion, especially as young adults navigate college for the first time. For example, while organizations such as Special Olympics or Best Buddies (both heavily discussed

throughout the study) are disability-centric (e.g., developed for individuals with disabilities to join and access), there is an accompanying requirement of “inclusion” which results in people without disabilities supporting those with disabilities (e.g., a peer buddy, or a nondisabled coach). Individuals with disabilities should be able to create their own spaces without a social requirement or definition of inclusion (e.g., being paired with someone without a disability), and if that is where they feel most included, then PSEs and community spaces need to allow for this.

In the college setting, there are endless opportunities for students to select choices and make decisions (e.g., which classes to take, who to live with, how to spend your free time, what to say *no* to, relationships). PSE administrators and staff can consider and adapt, as appropriate, the deep well of research on decision-making and self-advocacy skills among young adults with IDD in high school settings. For example supported decision-making and person-centered planning protocols center the individual with IDD and provide potential assessments, accommodations, and interventions to allow for independent choice-making in a supportive environment (Bigby et al., 2019, Shogren & Wehmeyer, 2015).

PSE program leadership needs to carefully consider choice across settings, how choices are presented, and when lack of choice(s) exist among PSE students. Additionally, providing an opportunity to make a decision is not the same as honoring a decision, particularly when forced choice is presented (e.g., presenting options without the opportunity to say no altogether). Forced choice, while potentially aimed at providing options and fostering decision making, can be as exclusionary as no choice, especially if

individual interests or needs are not considered. Training should be provided to PSE program staff which focuses on the importance of autonomy, choice theory (choices based on survival, belonging, power, freedom, and fun; Glasser, 1998), and choice as a basic need of human rights and inclusion. PSEs should critically examine forced choice built into the program and how that aligns or misaligns with program philosophy and purpose. Engaging in reflexivity practices to identify potentially ableist structures may result in new opportunities, and deconstruction of barriers to choice. Likewise, identifying situations that lack choice (e.g., staff “letting us do different things,” “not allowed”) and redesigning to develop action plans for students when they feel as if they have no choice. This can begin before college through choice-making and self-advocacy practice.

Last, EFR members could provide examples of places, times, and people in their stories of inclusion, but never formally defined the construct. These experiences should be taken as truth, and add to the conceptualization of inclusion—that there are positive feelings associated with it. When an expert in the community can say “this was inclusion because I felt it,” it should be noted.

Implications for Research

This study explored perspectives of inclusion at the college setting while utilizing/designing accessible research procedures to increase participation of individuals with IDD. The pervasive distrust of individuals with IDD contributing to research and knowledge making mirrors EFR member stories of wanting/needing to be heard, given permission, and validated as active members in their college communities. However,

individuals with IDD are among the vulnerable populations who have been historically harmed by, exploited by, or simply left out of research (Reed & Francis, 2021). Further, research indicates that including individuals with IDD in research is often met with barriers related to inaccessibility (e.g., literacy level, background knowledge of research or research question) and institutional guidelines (e.g., IRB restrictions, participation with/out guardian consent) so they do not do it. Future research must continue to press the boundaries of who and what constitutes research and knowledge making.

Additionally, if the intent is to contribute research that includes the voice of individuals with IDD, future studies need to include more voices.

Use of visual strategies can support understanding and increase participation in research, especially when working with individuals with IDD (Francis et al., 2020; Ming et al., 2021; Tilley et al., 2021). Additionally, professionals can use methods such as a visual data interviews during person-centered planning or IEP meetings where individuals can use artifacts to discuss experiences and memories and how they relate to future goals.

Future research should continue to focus/center on perspectives of individuals with IDD and their experiences with inclusion. This may lead to clearer conceptualizations of what makes individuals “feel” inclusion versus what professionals determine to be inclusion (quantity of time, proximity to others, or the subject matter): Without individuals’ input and experiences those definitions lack expert knowledge.

EFR members shared varying—and at times conflicting—stories related to inclusion and inclusive opportunities. Selecting specific areas of life through which to

investigate inclusion (e.g., school, residential housing, accessing community, employment) may provide more practical or meaningful findings as opposed to a broad generalization of the concept. For example, investigating the importance of feeling inclusion within independent/supported living and housing may provide PSE staff with improved program guidelines or objectives. Future research should focus on the wants, needs, and recommendations of individuals with IDD living in campus communities and develop objectives for teaching skills, facilitating interpersonal relationships, or create action plans for conflict or crisis. Additionally, research which includes more participants or longer data collection periods may allow a deeper investigation of “inclusion” within and after PSEs as a PSE outcome. Research should also aim at developing a socially valid way to measure satisfaction, including conducting an appreciative inquiry on a PSE with focus on student choices and levels of satisfaction.

Additionally, future research should focus on post-PSE program outcomes. Independent living outcomes reported in this study (e.g., Mary requesting paid staff support but not parent help, Teddy’s excitement to live with chosen roommates) indicates future research should investigate to what degree “inclusion” had an impact in postprogram living settings.

Research with and alongside individuals with IDD should continue to take place in virtual and in-person settings. The lack of physical meetings for the EFR team due to COVID-19 prevented some additional opportunities for meaningful/tangible/accessible data collection (e.g., graffiti walls, physical manipulation of ideas and themes, card sorting) as well as the opportunity for deeper relationship building. However, online

platform meeting rooms allowed EFR members to participate comfortably from their homes without the burden of transportation.

Last, the EFR research group may serve as a model for future collectives with the priority of including individuals with disabilities at each stage in the research process through collaboration on protocol development and data collection tools as well as creating publication materials. Relatedly, future researchers should reconsider what constitutes publication and dissemination, and continue to increase accessibility of findings.

Appendix for First Manuscript

Semi-Structured Individual Interview/Conversation

Thank you so much for meeting with me today. I will be recording this conversation so that I can remember what we talk about, and we can go back and watch it together anytime you want. If you ever want to take a break or stop talking, that's just fine. Does that make sense?

Great let's get started!

So I already know a little bit about you, like _____ (draw from personal relationship and background knowledge) but let's start by learning a little more!

- *Where from/age/family/current living situation*
- *What PSE did you attend? When?*

Like I said in our group meeting, and in my emails/FB messages, I am really excited to work with you and listen to your stories/experiences! I know I have shared with you that I'm interested in inclusion, but I also want to learn about your time at the PSE program and what life is like now! Reed: I want to talk about your time at [Program Name] today. When did you attend the program?

Can you tell me why you wanted to come to the program?

What are some things you liked about the program? What are some things you didn't like?

I am a teacher, and I used to work at a program just like this one. We always talked about inclusion. Have you heard of that word before? Where? Who uses it? Do you hear it now that you are out of school?

When you hear the word inclusion, what do you think of? Can you tell me the definition of inclusion? What do you think inclusion means? What does it mean in school? College?

Back up plan: Okay, what if we call inclusion this _____.

Tell me about a time you felt inclusion at [Program name]

- *Can you tell me about who you were with?*
- *Can you tell me about what you were doing?*
- *Can you tell me about how you were feeling?*

Tell me about a time you didn't feel inclusion at [Program name] What did you not get to do? What could you change?

- *Can you tell me about who you were with?*
- *Can you tell me about what you were doing?*
- *Can you tell me about how you were feeling?*
- *How could you make that better?*

Now I'd love to talk about your life now, after [Program name]!

- *Where are you living? Who with? Tell me a little about your living situation.*
- *Tell me about your employment/job experience. Do you have a job?*
- *What do you do in your spare time? Who do you spend time with?*

When do you feel inclusion now?

Are there times you don't feel inclusion?

If you were in charge of [Program name], what would you do about inclusion?

Do you have suggestions for your [Program director name] or teachers?

Semi-Structured Individual Interview/Conversation II

Thank you so much for meeting with me today. I will be recording this conversation so that I can remember what we talk about, and we can go back and watch it together anytime you want. If you ever want to take a break or stop talking, that's just fine. Does that make sense?

Great let's get started!

So the last time we talked just the two of us we talked about... (review based on notes)

- *What was your favorite part of our discussion?*
- *Anything you didn't like?*

I'm hoping we can dive a little deeper into stories about inclusion today, are you okay with that?

Review purpose of study: You recently completed a college program designed for individuals with disability, I want to hear about your experiences

What were some things you liked about the program? What are some things you didn't like?

When you hear the word inclusion, what do you think of? Can you tell me the definition of inclusion? What do you think inclusion means? What does it mean in school? College?

Last time you mentioned feeling inclusion at _____.

- *Do you have any other memories from that time or that day?*
- *How did you end up at _____ (time/place)*

Is there another time you felt inclusion?

- *Who were you with? What were you doing? Can you tell me about how you were feeling?*

You also shared about _____ when you didn't feel inclusion

- *Do you have any other memories from that time or day?*
- *How did you end up at _____ (time/place)*

Now I'd love to hear how you are feeling with the research group. Any suggestions?

Recommendations?

- *What is your favorite part of our research group?*
- *Least favorite?*
- *Do you want to talk about anything in our next meeting?*
- *What should we do with our work together?*
 - *Do you want to keep meeting?*

Semi-Structured Individual Interview or Group Conversation III

Thank you so much for meeting with me today. I will be recording this conversation so that I can remember what we talk about, and we can go back and watch it together anytime you want. If you ever want to take a break or stop talking, that's just fine. Does that make sense?

Great let's get started!

So I already know a little bit about you, like _____ (draw from personal relationship and what learned so far in study) but let's review a little

- *How are you feeling so far about our research group?*
- *Is there anything you want to talk about today?*

Today we will review a little from our group talks, and also talk about Dream College and Dream Living. We can also talk about things you want.

Can you tell/show me your Dream College ideas?

- *Can you tell me more about (classes/friends/housing)*
- *What is the most important part?*
- *Why did you pick _____ (location, classes, friends)*

Can you tell/show me your Dream Living?

- *Can you tell me more about (roommate, family, pet)*
- *Why did you pick (location, roommate)*
- *You mentioned _____ (detail), it sounds like _____ is important. Can you share more?*

Tell me about what you feel or think when you hear Inclusion

- *Do you want to add anything?*
- *If positive: Can you tell me a story about a [positive word they used]*
- *If negative: Can you tell me a story about a [negative word they used]*

Now I'd love to talk about our research together, and hear ideas!

- *What is your favorite part of our research group?*
- *Least favorite?*
- *Do you want to talk about anything in our next meeting?*
- *What should we do with our work together?*
 - *Do you want to keep meeting?*

Semi-Structured Initial Group Protocol

Schedule group Zoom meeting at a time where all # participants can attend, plan for 1hr of meeting time.

Thanks everyone so much for meeting with me today. I will be recording this conversation so that I can remember what we talk about, and we can go back and watch it anytime! The video will be private though, only the people on this call can see or hear it. If you ever want to take a break or stop talking, that's just fine. You also can turn your camera off too, so that just your voice is being recorded! Does that make sense?

ICEBREAKER

Great let's start with some introductions! How about everyone starts with introducing yourselves—tell us the name you want us to call you, what program or college you went to after high school, where you live now, and one happy thought! I'll go first. My name is Sascha, after high school I went to college in California and now I'm in school at George Mason. I live in Ashburn, Virginia now, and one thing I am happy about right now is

_____.

Prompt as needed to make sure all participants who want to participate are able to.

INTRODUCTION

Great to meet/see everyone! So I wanted us all to have a chance to meet and chat together before our project starts. All of you are on this call because you agreed to work on a project with me about learning about inclusion for young adults with disabilities. Today if it is okay with everyone I was hoping we could have a group meeting where we got to know each other better, or catch up with people we haven't seen in awhile. The spring/summer has been really crazy with COVID-19 and social distancing, so I wanted us to have a social zoom time right now. We can talk about inclusion, and college, but we can also just hang out and talk about whatever!

IF CONVERSATIONS DO NOT START NATURALLY, FOLLOWING PROMPTS WILL BE USED:

We can start with some questions or ideas about the project. Does anyone have any questions for me since I am the one who reached out to you about being a part of this project?

I am in school right now to become a researcher, and I'm really interested in special education, disability studies, inclusion, and working with people with disabilities. It is important to me that people with disabilities are a part of research.

- *Has anyone ever worked on a project like this?*

- *Been on a research team?*
 - *Experiences with research?*
- *Is anyone interested in doing research?*
- *What is important to know about people with disabilities/Inclusion/research*

Inclusion: *So I really want to learn about inclusion from everyone. What kind of questions should I ask about inclusion?* General conversation/topic probes

Who has roommates? What's great/not great about living situation?

Work? COVID-19 impact?

Special Olympics: no fall sports this year, how is Fitness Combine going?

Upcoming plans/Favorite summer stories/memories

Semi-Structured Group Protocol

To be used as facilitation of group discussions, as needed.

Thanks everyone so much for meeting again. I will be recording this conversation so that I can remember what we talk about, and we can go back and watch it anytime! The video will be private though, only the people on this call can see or hear it. If you ever want to take a break or stop talking, that's just fine. You also can turn your camera off too, so that just your voice is being recorded! Does that make sense?

ICEBREAKER/WELCOME/INTRODUCTION

Great to meet/see everyone again! The last time we met, we (review prior discussions)

Something I noticed was a lot of talk about ____ (modeling finding patterns or refrains)

Who else noticed anything about conversation

IF CONVERSATIONS DO NOT START NATURALLY, FOLLOWING PROMPTS CAN BE USED:

(Review as needed): *I'm really interested in special education, disability studies, inclusion, and working with people with disabilities. It is important to me that people with disabilities are a part of research.*

- *How is everyone feeling about our meetings and research so far?*
 - *Any feelings about being co-researchers/*
- *Does anyone have any new ideas or questions?*

Discussion prompts/starters:

I was wondering if ____ (all or one person) could share more about ____.

-Does anyone else want to add, or have another story?

Inclusive memories

Positive memories of courses, friends, activities, staff

-Favorite event on campus/Favorite event you went to during college

Wish I could have changed ____ (courses, friends, activities, staff, other)

-Negative feelings? Feeling left out

What is the most important thing to share about inclusion?

Concluding/checking in:

How does everyone feel about today's talk? About the group?

Do you want to meet again?

____ will lead the next meeting (as needed).

Semi-Structured Individual Interview/Conversation: Visual Analysis

SHOWeD Method (Wang & Burris' (1997) integration of Schaffer, 1983)

*What do you **See** here?*

*What is really **H**appening here?*

*How does this relate to **O**ur lives?*

***W**hy does this concern, situation, or strength exist?*

*How can we become **E**mpowered through our new understanding?*

*And, what can we **D**o?*

SHIMeT Protocol (adapted)

Thank you so much for meeting with me today. I will be recording this conversation so that I can remember what we talk about, and we can go back and watch it together anytime you want. If you ever want to take a break or stop talking, that's just fine. Does that make sense?

Great let's get started!

So today I would love to take a look at the photo or picture you want to share. We will be looking at it together on the screen.

Share screen/make image visible

*First, let's just talk about what we **See** here? (follow up probes/prompts as necessary)*

- *what/who is in the picture?*
- *What can we see? I see ...*

*Next, what was **H**appening in the picture?*

- *How did you get to ____?*
- *Why were you with ____?*
- *Who was taking the picture?*
- *What were you thinking about when you drew this (if photo)*

*What makes this **I**important for **I**nclusion?*

- *Why does this make you think of inclusion?*
- *What was inclusion in the photo?*

*What is the **M**emory behind this?*

- *What do you remember about this photo/place/person*
- *Do you remember how you were feeling?*
 - *How the others were feeling?*

*What can this **T**each or **T**ell us about inclusion?*

- *How can this help people learn about inclusion*
 - *What else is inclusion here?*
- Lastly: Any other reason you wanted to share this picture?*

References for First Manuscript

- Abbott, S., & McConkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities, 10*(3), 275–287.
- Agarwal, R., Heron, L., & Burke, S. L. (2021). Evaluating a postsecondary education program for students with intellectual disabilities: Leveraging the parent perspective. *Journal of Autism and Developmental Disorders 51*, 2229–2240. <https://doi.org/10.1007/s10803-020-04676-0>
- Agran, M., Brown, F., Hughes, C., Quirk, C., & Ryndak, D. (Eds.). (2014). *Equity and full participation for individuals with severe disabilities: A vision for the future*. Brookes.
- American Association on Intellectual and Developmental Disabilities. (2020). *Inclusion: Joint position statement of AAIDD and the Arc*. <https://www.aaid.org/news-policy/policy/position-statements/inclusion>
- Becht, K., Roberts-Dahm, L. D., Meyer, A., Giarrusso, D., & Still-Richardson, E. (2020). Inclusive postsecondary education programs of study for students with intellectual disability. *Journal of Postsecondary Education and Disability 33*, 63–79. <https://files.eric.ed.gov/fulltext/EJ1273630.pdf>
- Bigby, C., Whiteside, M., & Douglas, J. (2019). Providing support for decision making to adults with intellectual disability: Perspectives of family members and workers in disability support services. *Journal of Intellectual and Developmental Disability, 44*(4), 396–409. <https://doi.org/10.3109/13668250.2017.1378873>
- Boutout, E. A., & Bryant, D. P. (2005). Social integration of students with autism in inclusive settings. *Education and Training in Developmental Disabilities, 40*, 14–23. <https://www.jstor.org/stable/23879768>
- Brock, M. E., & Huber, H. B. (2017). Are peer support arrangements an evidence-based practice? A systematic review. *The Journal of Special Education, 51*(3), 150–163. <https://doi.org/10.1177/0022466917708184>
- Bronkema, R. H., & Bowman, N. A. (2019). Close campus friendships and college student success. *Journal of College Student Retention: Research, Theory & Practice, 21*(3), 270–285. <https://doi.org/10.1177/1521025117704200>

- Browder, D. M., Spooner, F., Ahlgrim-Delzell, L., Harris, A. A., & Wakeman, S. (2008). A meta-analysis on teaching mathematics to students with significant cognitive disabilities. *Exceptional Children, 74*(4), 407–432. <https://doi.org/10.1177/00144029080740040>
- Call-Cummings, M., Hauber-Özer, M., Byers, C., & Mancuso, G. (2019). The power of/in Photovoice. *International Journal of Research and Method in Education, 42*(4), 399–413. <https://doi.org/10.1080/1743727X.2018.1492536>
- CAST. (2018). *Universal design for learning guidelines version 2.2*. <http://udlguidelines.cast.org>
- Carter, E. W., Moss, C. K., Asmus, J., Fesperman, E., Cooney, M., Brock, M. E., Lyons, G., Huber, H. B., & Vincent, L. B. (2015). Promoting inclusion, social connections, and learning through peer support arrangements. *Teaching Exceptional Children, 48*, 9–18. <https://doi.org/10.1177/0040059915594784>
- Carter, E. W., Gustafson, J. R., Mackay, M. M., Martin, K. P., Parsley, M. V., Graves, J., Day, T. L., McCabe, L. E., Lazarz, H., McMillan, E. D., Schiro-Geist, C., Williams, M., Beeson, T., & Cayton, J. (2019). Motivations and expectations of peer mentors within inclusive higher education programs for students with intellectual disability. *Career Development and Transition for Exceptional Individuals, 42*(3), 168–178. <https://doi.org/10.1177/2165143418779989>
- Cheak-Zamora, N. C., Teti, M., & Maurer-Batjer, A. (2018). Capturing experiences of youth with ASD via photo exploration: Challenges and resources becoming an adult. *Journal of Adolescent Research, 33*, 117–145. <https://doi.org/10.1177/2F0743558416653218>
- Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry: Experience and story in qualitative research*. Jossey-Bass Publishers.
- Collins, E. C. (1992). Qualitative research as art: Toward a holistic process. *Theory Into Practice, 31*(2), 181–186. <https://doi.org/10.1080/00405849209543540>
- Collins, H. (2018). Studies of expertise and experience. *Topoi, 37*, 67–77. <https://doi.org/10.1007/s11245-016-9412-1>
- Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among the five approaches* (3rd ed.). Sage.
- Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry and research design: Choosing among five approaches* (4th ed.). Sage.
- Education for All Handicapped Children Act, Pub. L. No. 94-142, § 601(c) (1975).

- Fals Borda, O., & Rahman, M. A. (1991). *Action and knowledge: Breaking the monopoly with participatory action-research*. Apex Press.
- Furnham, A. (1986). Response bias, social desirability and dissimulation. *Personality and Individual Differences*, 7(3), 385–400. [https://doi.org/10.1016/0191-8869\(86\)90014-0](https://doi.org/10.1016/0191-8869(86)90014-0)
- Fine, M., & Torre, M. E. (2004). Re-membering exclusions: Participatory action research in public institutions. *Qualitative Research in Psychology*, 1, 15–37. <https://doi.org/10.1191/1478088704qp003oa>
- Francis, G. L., Reed, A. S., & Howard, M. E. (2020). Interactions with and between families and professionals in college: Perspectives of young adults with intellectual and developmental disabilities. *Inclusion*, 8(2), 163–179. <https://doi.org/10.1352/2326-6988-8.2.163>
- Glasser, W. (1998). *Choice theory: A new psychology of personal freedom*. Harper Collins.
- Grigal, M., Hart, D., Smith, F. A., Domin, D., Sulewski, J., & Weir, C. (2014). *Think College National Coordinating Center: Annual report on the transition and postsecondary programs for students with intellectual disabilities (2012–2013)*. University of Massachusetts Boston, Institute for Community Inclusion.
- Hall, S. (2009). The social inclusion of young adults with intellectual disabilities: A phenomenology of their experiences. *Journal of Ethnographic and Qualitative Research*, 4, 24–40. <https://eric.ed.gov/?id=EJ906605>
- Higher Education Opportunity Act, Pub. L. No. 110-315, 122 Stat. 3078 (2008).
- Hollomotz, A. (2018). Successful interviews with people with intellectual disability. *Qualitative Research*, 18(2), 153–170. <https://doi.org/10.1177/1468794117713810>
- Individuals With Disabilities Education Improvement Act, H.R. 1350, Pub. L. No. 108–446 (2004).
- Individuals With Disabilities Education Improvement Act of 2004, 20 U.S.C. § 1400 et seq. <https://www.congress.gov/bill/108th-congress/house-bill/1350>
- Jurkowski, J. (2008). Photovoice as action research tool for engaging people with intellectual disabilities in research and program development. *Intellectual and Developmental Disabilities*, 46, 1–11. [https://doi.org/10.1352/0047-6765\(2008\)46\[1:PAPART\]2.0.CO;2](https://doi.org/10.1352/0047-6765(2008)46[1:PAPART]2.0.CO;2)

- Kemmis, S., & McTaggart, R. (2007). Participatory action research: Communicative action and the public sphere. In N. D. Denzin & Y. S. Lincoln (Eds.), *Strategies of qualitative inquiry* (4th ed., pp. 271–330). SAGE.
- Kersh, J., Corona, L., & Siperstein, G. (2013). Social well-being and friendship of people with intellectual disability. In M. L. Wehmeyer (Ed.), *The Oxford handbook of positive psychology and disability* (pp. 60–81). Oxford University.
- Kurth, J. A., Lyon, K. J., & Shogren, K. A. (2015). Supporting students with severe disabilities in inclusive schools: A descriptive account from schools implementing inclusive practices. *Research and Practice for Persons with Severe Disabilities*, 40(4), 261–274. <https://doi.org/10.1177/1540796915594160>
- Kurth, J. A., & Mastergeorge, A. M. (2010). Individual education plan goals and services for adolescents with autism: Impact of age and educational setting. *The Journal of Special Education*, 44, 146–160. <https://doi.org/10.1177/0022466908329825>
- Kurth, J. A., Morningstar, M. E., & Kozleski, E. B. (2014). The persistence of highly restrictive special education placements for students with low-incidence disabilities. *Research and Practice for Persons with Severe Disabilities*, 39(3), 227–239. <https://doi.org/10.1177/1540796914555580>
- Lee, C. E., & Taylor, J. L. (2021). A review of the benefits and barriers to postsecondary education for students with intellectual and developmental disabilities. *The Journal of Special Education*, 55, 234–245. <https://doi.org/10.1177/002246692110133>
- Limes-Taylor Henderson, K., & Esposito, J. (2019). Using others in the nicest way possible: On colonial and academic practice(s), and an ethic of humility. *Qualitative Inquiry*, 25(9–10), 876–889. <https://doi.org/10.1177/1077800417743528>
- Maslow, A. H. (1943). A theory of human motivation. *Psychological Review*, 50(4), 370–396. <https://dx.doi.org/10.1037/h0054346>
- McCabe, K. M., Ruppert, A., Kurth, J. A., Mcqueston, J. A., Johnston, R., & Toews, S. G. (2020). Cracks in the continuum: A critical analysis of least restrictive environment for students with significant support needs. *Teachers College Record*, 122(5), 1–28. <https://doi.org/10.1177/01614681201220051>
- Merriam, S. B. (1998). *Qualitative research and case study applications in education* (2nd ed.). Jossey-Bass.
- Merriam, S. B., & Tisdell, E. J. (2016). *Qualitative research: A guide to design and implementation* (4th ed.). Jossey-Bass.

- Ming, J., Heung, S., Azenkot, S., & Vashistha, A. (2021, October). *Accept or address? Researchers' perspective on response bias in accessibility research* (Article No. 20 1-13). ASSETS '21: The 23rd International ACM SIGACCESS Conference on Computers and Accessibility. <https://doi.org/10.1145/3441852.3471216>
- Montoya, R. M., Horton, R. S., & Kirchner, J. (2008). Is actual similarity necessary for attraction? A meta-analysis of actual and perceived similarity. *Journal of Social and Personal Relationships*, 25(6), 889–922. <https://doi.org/10.1177/0265407508096700>
- Nind, M., & Vinha, H. (2014). Doing research inclusively: Bridges to multiple possibilities in inclusive research. *British Journal of Learning Disabilities*, 42(2), 102–109. <https://doi.org/10.1111/bld.12013>
- O'Grady, G., Clandinin, D. J., & O'Toole, J. (2018). Engaging in educational narrative inquiry: Making visible alternative knowledge. *Irish Educational Studies*, 37(2), 153–157. <https://doi.org/10.1080/03323315.2018.1475149>
- Patton, M. Q. (2015). *Qualitative research and evaluation methods* (4th ed.). Sage.
- Plotner, A. J., & Marshall, K. J. (2015). Postsecondary education programs for students with an intellectual disability: Facilitators and barriers to implementation. *Intellectual and Developmental Disabilities*, 53, 58–69. <https://doi.org/10.1352/1934-9556-53.1.58>
- Povee, K., Bishop, B. J., & Roberts, L. D. (2014). The use of Photovoice with people with intellectual disabilities: Reflections, challenges, and opportunities. *Disability and Society*, 29(6), 893–907. <https://doi.org/10.1080/09687599.2013.874331>
- Prohn, S. (2014). *A grounded theory of social inclusion for postsecondary education students with intellectual disability* (UMI No1 3690350) [Doctoral dissertation]. ProQuest Dissertations and Theses.
- Qian, X., Clary, E., Johnson, D. R., & Echternacht, J. K. (2018). The use of a coaching model to support the academic success and social inclusion of students with intellectual disabilities in community and technical college settings. *Journal of Postsecondary Education and Disability*, 31(3), 193–208. <https://doi.org/10.1177/2165143420929655>
- Reed, A. S., & Francis, G. L. (2021). Considerations for engaging in research with individuals with disabilities. In C. C Reyes, S. J. Haines, & K. Clark-Keefe (Eds.), *Humanizing methodology: Culturally appreciative methods for working with vulnerable populations in qualitative research* (pp. 110–117). Teachers College Press.

- Riessman, C. K. (2008). *Narrative methods for the human sciences*. Sage.
- Saldana, J. (2016). *The coding manual for qualitative researchers* (3rd ed.). Sage.
- Schaffer, R. (1983). *Beyond the dispensary*. Nairobi: AMREF (The African Medical and Research Foundation).
- Schallock, R. L., Keith, K. D., Verdugo, M. A., & Gomez, L. E. (2010). Quality of life model development and use in the field of intellectual disability. In R. Kober (Ed.), *Quality of life: Theory and implementation* (pp. 17–32). Sage.
- Schmidt, S. (2020). The importance of friendships for academic success. *Journal of Food Science Education* 19, 2–5. <https://doi.org/10.1111/1541-4329.12176>
- Slee, R. (2019). Belonging in an age of exclusion. *International Journal of Inclusive Education*, 23(9), 909–922. <https://doi.org/10.1080/13603116.2019.1602366>
- Shogren, K. A., & Wehmeyer, M. L. (2015). A framework for research and intervention design in supported decision-making. *Inclusion* 3, 17–23. <https://doi.org/10.1352/2326-6988-3.1.17>
- St. John, B., Mihaila, I., Dorrance, K., DaWalt, L. S., & Auserdau, K. K. (2018). Reflections from co-researchers with intellectual disability: Benefits to inclusion in a research study team. *Intellectual and Developmental Disabilities* 56(4), 251–262. <https://doi.org/10.1352/1934-9556-56.5.251>
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Sage.
- Tilley, E., Strnadova, I., Ledger, S., Walmsley, J., Loblinzk, J., Christian, P. A., & Arnold, Z. J. (2021). “Working together is like a partnership of entangled knowledge”: Exploring the sensitivities of doing participatory data analysis with people with learning disabilities. *International Journal of Social Research Methodology*, 24(5), 567–579. <https://doi.org/10.1080/13645579.2020.1857970>
- Uditsky, B., & Hughson, E. (2012). Inclusive postsecondary education—An evidence-based moral imperative. *Journal of Policy and Practice in Intellectual Disabilities* 9(4), 298–302. <https://doi.org/10.1111/jppi.12005>
- Walmsley, J., Strnadova, I., & Johnson, K. (2017). The added value of inclusive research. *Journal of Applied Research in Intellectual Disabilities*, 31(5), 751–759. <https://doi.org/10.1111/jar.12431>

- Wang, C. C. (1999). Photovoice: A participatory action research strategy applied to women's health. *Journal of Women's Health, 8*(2), 185–192.
<https://doi.org/10.1089/jwh.1999.8.185>
- Wang, C. C. (2006). Youth participation in Photovoice as a strategy for community change. *Journal of Community Practice, 14*, 147–161.
https://doi.org/10.1300/J125v14n01_09
- Wang, C. C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior, 24*(3), 369–387.
https://doi.org/10.1177_109019819702400309
- Wehmeyer, M. L., Palmer, S. B, Shogren, K. A., Williams-Diehm, K., & Soukup, J. (2013). Establishing a causal relationship between interventions to promote self-determination and enhanced self-determination. *Journal of Special Education 46*(4), 195–210. <https://doi.org/10.1177/0022466910392377>
- Weir, C., Grigal, M., Hart, D. and Boyle, M. (2013). *Profiles and promising practices in higher education for students with intellectual disability*. Think College. University of Massachusetts Boston, Institute for Community Inclusion.

**Inclusion is Choice:
Recommendations to Increase Inclusive Experiences at the Postsecondary Setting**

Abstract

Now, more than ever, students with intellectual and developmental disabilities (IDD) are attending college through inclusive postsecondary education (IPSE) programs. IPSEs are nondegree higher education programs designed specifically for students with IDD to participate in all aspects of college life. Research has focused on documenting the structure of these programs as well as program completion outcomes. Limited research exists which includes individuals with IDD as participants or co-researchers, despite their lived experience in attending an IPSE. This phenomenological and participatory inquiry attempted to understand the inclusive experiences of eight young adults with IDD who had completed an IPSE. Recommendations for choice to increase inclusive experiences are shared.

Keywords: intellectual and developmental disability, inclusive postsecondary program, choice

Inclusion in primary and secondary education settings (e.g., “individuals learning in their neighborhood school in a general education classroom that contains children of the same age without disabilities”; AAIDD, 2020) has led to opportunities for students with intellectual and developmental disabilities (IDD), or individuals with disabilities with significant limitations in both intellectual functioning and adaptive behavior which originate before the age of 22 (AAIDD, 2021), to attend inclusive postsecondary education programs at institutions higher education among their peers without disabilities (Mazzotti et al., 2021; Whirley et al., 2020). Inclusive postsecondary education programs (IPSE) are nondegree higher education programs designed specifically for students with IDD (Think College National Coordinating Center Accreditation Workgroup, 2021). As with research demonstrating academic gains, increased socialization and communication, and increased self-advocacy among students with disabilities in elementary and secondary school (Agran et al., 2020; Kurth & Mastergeorge, 2010; Shogren et al., 2017), research on IPSEs indicates individuals who participate demonstrate substantially better outcomes in employment, social engagement, community living, and functional academic skills (Lee & Taylor, 2022; Mazzotti et al., 2021). The increase in the number of IPSEs across the country in the last 25 years has led to research targeting enhancing IPSE programs and graduate outcomes (Whirley et al., 2020). IPSE-related research including the perspectives of IPSE students with IDD, however, is lacking (Carter & Bumble, 2018; Prohn, 2014). This is concerning, given the critical nature of learning directly from individuals with direct experience regarding programmatic activities and outcomes (Lund et al., 2022; McDonald & Kidney, 2012). As a result, it is imperative that researchers

report the firsthand accounts of individuals who attended IPSEs when considering policy or program recommendations or changes. Therefore, the purpose of this study was to understand recommendations for positive inclusive experiences at the postsecondary setting from the perspectives of young adults with IDD who graduated from an IPSE program through collaborative and participatory inquiry.

The Emergence of IPSEs

The reauthorization of the Higher Education Act of 1965 as the Higher Education Opportunity Act (HEOA, 2008) included several important provisions aimed at changing postsecondary outcomes for students with IDD. Under HEOA, students with IDD became eligible for federal funding (e.g., Pell Grant, Federal Work-Study, Federal Supplemental Education Opportunity Grants) to assist with tuition to attend programs at institutes of higher education. While not solely focused on inclusion, this legislation provided the first opportunity for students with IDD to access postsecondary settings such as college programs, an experience from which they have traditionally been excluded.

According to Think College National Coordinating Center Accreditation Workgroup (2021) there are 310 PSEs nationwide (doubled from 2008 when HEOA was passed) but not all claim to be inclusive. Consistent with the reauthorization of the Higher Education Opportunity Act (HEOA, 2008) the emphasized participation in inclusive college courses and internships and required students with IDD to be integrated socially and academically to the maximum extent possible—IPSEs, and must be: (a) offered by a college or career school and approved by the U.S. Department of Education; (b) designed to support students with IDD to continue academic, career, and independent living

instruction in order to prepare for gainful employment; and must (c) require with IDD to interact with nondisabled peers for 50% of the time spent in the program (HEOA, 2008). Typically, IPSEs are four-year programs on university campuses aimed at providing students with IDD an inclusive college experience, including college course participation, campus organization membership, work experiences, and the option for residential housing on campus. However, there are other options and service delivery formats including two-year community college programs with or without degree options and four-year commuter programs (Avellone et al., 2021; Neubert et al., 2001).

The expansion of IPSE programming and development of model comprehensive transition programs for individuals with IDD as a priority under HEOA has led to an increased research focus on IPSE programming, structure, and transition (Walte et al., 2017). Much of the research on IPSEs is focused on positive postschool outcomes for individuals with IDD upon graduation. Academic gains across content areas, employment opportunities, and increased independent living and self-advocacy skills are among the widely applauded benefits of these programs (Grigal et al., 2018; Parisi & Landau, 2019; Plotner & Marshall, 2015). Though this wave of research on IPSEs brought students with IDD into the forefront of the IPSE discussion, few studies have sought to understand and evaluate IPSEs from the perspectives of individuals with IDD who attended an IPSE (Francis et al., 2020; Paiewonsky, 2011; Prohn, 2014). The minimal research that does include IPSE students as participants reinforces the importance of learning directly from this population as: (a) including students with IDD in research on IPSEs will lead to more accurate knowledge of impactful policy changes (Paiewonsky, 2011); (b) there exists a

notable difference in perspectives between students with IDD and college students without disabilities serving in supportive roles, thereby compromising an accurate understanding of the state of IPSEs (Prohn, 2014); and (c) including the perspectives and recommendations of students with IDD is necessary to appropriately and effectively inform IPSE programming (Francis et al., 2020).

Within the small but promising body of research on IPSEs which includes the perspectives of individuals with IDD, little focuses on the perspectives or experiences of inclusion. IPSEs are presented as inclusive, as defined by stakeholders other than the student (e.g., organizations, faculty, time requirements), yet the primary stakeholder and expert is not providing input or informing programmatic decisions. The present study sought to investigate recommendations and expectations of inclusive experiences at the postsecondary level from young adults with IDD who attended an IPSE. The research question guiding this work was: What are recommendations for inclusive college experiences from individuals with IDD?

Methods

This study sought to follow participatory methods, with a goal of “inclusive” research as its North Star because it acknowledges and welcomes participants with disabilities having unique needs to access the work, and that the contributions are valuable and worth representation (Strnavodá & Walmsley, 2018). However, the PI acknowledges that the methods did not fully adhere to true participatory methodology. For example, significant portions of the research process were planned and created without participant input, including the development of research questions and protocols,

and initial analysis procedures. Participants were recruited by, and the study was initially designed and conceived by, the PI and not a product of community organization or conversations. Despite lacking a community request for change or organization, this study was designed to be flexible and participant-focused. Power dynamics and imbalances were explicitly defined and discussed between the PI and participants in order to address, acknowledge, and proceed with the study. For example, PI-generated research questions led the study initially, but participants drove conversation directions and led to new areas of focus.

Design

A phenomenological design with narrative and participatory inquiry approaches was employed throughout this study. Emphasis was placed on participatory design in order to meet the needs and expectations of the research group. Data collection and analysis were iterative and collaborative, with participants actively involved in each stage of the research process. Participant engagement and involvement was individual (e.g., determined by each individual), however, and based on preference and comfort level. Some participants provided more information such as detailed stories, multiple forms of data, and frequent communication; some chose to observe and listen with little verbal or written input; some preferred one-on-one conversations throughout data collection.

Procedures

Research study procedures, activities, and timeline (outlined in Table 1) followed a qualitative participatory approach of ongoing data collection and analysis through interviews, group discussions, and visual analysis activities over Zoom meetings. The

study took place over the course of seven months following IRB requirements of electronic communication and no face-to-face contact during the international health pandemic. In total, the research group met 14 times in group settings and each member participated in at least 1 individual interview. All interviews and group discussions were audio- and video-recorded with the option for members to turn off the camera function as needed. Group and individual meeting recordings were transcribed using Zoom and Rev.Com software.

Table 1*Zoom Research Activities and Procedures*

| Week(s) | Purpose | Activity | Research Tools | EFR Co-facilitators |
|---------|--|---|--|---|
| 1-2 | Rapport building, introduce concepts and vocabulary | Group Discussions 1:1 Interviews | Semi-structured protocol, Icebreaker conversation starters, Semi-structured Interview Protocol | None. PI-led group discussions |
| 3 | Review study purpose, set goals, begin data collection | Group Discussions 1:1 Interviews | Semi-structured Interview Protocol 1 | None. PI-led group discussions and interviews |
| 4-6 | Data collection Data Analysis (PI) | Group Discussions Modeling analysis ^a | Member-generated protocols “Inclusion is...” prompt (menti.com Word Cloud) | EFR Member-led meetings: Ann, Veronica, Mary |
| 7 | Check-in Data collection Data analysis (PI) | Group Discussions 1:1 Discussions Modeling analysis | “Belonging is...” prompt (menti.com Word Cloud) | None. Open discussion |
| 8 & 9 | Data collection | Group Discussions Modeling analysis | Member-generated protocols | EFR Member-led meetings: Yahya, Lara |
| 10 & 11 | Data Collection Group Data Analysis | Thematic analysis discussion, visual analysis discussion | Dream Protocol, SHIMeT protocol, Visual data, Transcriptions, Audio and Video clips | None. PI-led analysis |
| 12 & 13 | Data Collection Group Data Analysis | Discussing themes, meaning behind stories | Visual data, Transcriptions, Audio and Video clips, Powerpoint of quotes | Open discussion |
| 14 | Analysis | 1:1 discussions Small group discussions | Visual data, Transcriptions, Audio and Video clips, Powerpoint of quotes | Open discussion |

Note. PI = primary investigator. This table outlines the general timeline of research procedures. Schedule and procedures remained fluid to reflect co-researcher interests and needs.

^a Modeling analysis indicates PI explicitly naming and explaining analysis procedures throughout the meeting (e.g., “I heard ___ five different times so I’m thinking this is important.”).

Participant Selection

Participants were recruited through convenience sampling from a local community group with which the PI volunteered and purposefully selected based on specific characteristics (Patton, 2015). Participants were selected based on the following inclusion criteria: (a) identified as an individual with IDD, (b) graduated from an IPSE, (c) expressed an interest and desire to participate in research project, (d) could independently access and navigate video conferencing tools (Zoom), (e) had access to technology for Zoom meetings (e.g., smartphone, tablet, computer), and (f) agreed to participate in recorded video and audio interviews and conversations (with the option to limit microphone or camera use). All individuals provided assent and those who served as their own guardians also provided consent. Legal guardians of interested participants (i.e., parents) were asked to provide consent via electronic forms and did not participate in study procedures. Participants provided written and verbal consent and those who did not serve as their own legal guardians were tasked with obtaining guardian consent as well. All research procedures and plans were provided in writing and verbally to potential participants, and guardians received written procedures.

Eight participants joined the study and formed the Everyday Friends Research Group (EFR) as co-researchers (and will hereon be referred to as such) with direct involvement with data collection, data analysis, and study procedures as is expected in participatory inquiry (Fals Borda & Rahman, 1991; Fine & Torre, 2004; Kemmis & McTaggart, 2005). While the term “co-researcher” is used, it is necessary to acknowledge that a power imbalance and hierarchy existed. The PI primarily served as the group lead,

scheduling meetings, setting up Zoom links, and providing conversation starters and prompts. Further, data collection and analysis procedures began with the PI leading discussions and modeling/teaching. For example, the PI engaged in independent analysis of data to develop preliminary codes to be shared with the group, and then shared the process with the group. Seven of the eight co-researchers graduated from a four-year IPSE program on a university campus within the area. The remaining co-researcher attended a two-year IPSE at a community college within the same geographical region. While the program differed, the student's contributions to the discussions and experiences shared were similar to the group. Co-researcher ages ranged from age 22 to 32. Six co-researchers were female and two were male. Five identified as White/Caucasian, one identified as Asian, one identified as Middle Eastern, and one did not disclose race/ethnicity identification. Additional co-researcher demographics and additional information can be found in Table 2.

Table 2*Everyday Friends Research Group Participant Demographic Information*

| Pseudonym | Age | Gender | Disability | Own Guardian | Ethnicity | Place of Residence | Currently Employed |
|-----------|-----|--------|-------------------------|--------------|----------------|-------------------------------------|--------------------|
| Sophia | 26 | Female | Autism | Yes | White | Home with family | Y |
| Rikki | 22 | Female | Seizure disorder | No | White | Home with family (NP) | N |
| Teddy | 22 | Male | Not shared | No | White | Community with chosen roommates (P) | Y |
| Veronica | 24 | Female | Down syndrome | No | White | Community with chosen roommates (P) | Y |
| Lara | 29 | Female | Intellectual disability | Yes | Not shared | Home with family (NP) | Y |
| Mary | 32 | Female | Intellectual disability | No | White | Home with family (NP) | Y |
| Ann | 27 | Female | Not shared | No | Asian | Home with family (P) | N |
| Yahya | 25 | Male | Down syndrome | No | Middle Eastern | Home with family (NP) | N ^a |

Note. Some names are pseudonyms as chosen by Everyday Friends Research Group (EFR) members. Information was provided by members and or guardians and confirmed by co-researchers during interviews. Place of residence was reported at time of interviews. P indicates “preferred setting” and NP indicates “nonpreferred” as reported by participants.

^a Laid off due to COVID-19.

Data Collection

The primary forms of data collection were individual and group interviews. Both types of interviews were informal and conversational in order to engage in authentic and realistic/naturalistic dialogue. Interviews were semi-structured with questions and probes used flexibly, depending on flow of conversation and co-researcher input. For example, protocol questions focused on inclusive experiences and stories from college, but many discussions led to sharing hopes or worries about the future. Additionally, when the group's energy or engagement seemed low (e.g., no one was offering to speak, yawning, decreased eye contact or chatbox communication) the PI shifted discussion to current events or suggested the meeting end early. All individual interviews followed a semi-structured interview protocol developed by the PI based on pilot study protocol feedback, and prior protocol and conversation tools used with young adults with IDD discussing college experiences (Francis et al., 2020; Appendix). The content of the first protocol invited members to first share general background information about attending a PSE program, followed by their personal definition of the term *inclusion* as well as personal experiences with inclusion while at a PSE. Next, participants were invited to share current information about their life, and lastly, participants were asked to give recommendations for a future or "dream" PSE program. Each EFR member participated in at least two formal individual interviews. The second individual interview incorporated an adapted Photovoice interview technique. Visual data, including drawings and personal photographs, were collected during interviews in hopes to include nonverbal or

nontextual representations of participant experience and increase the means for expression and representation (CAST, 2018).

Group Interviews

Group interviews took place weekly on Monday evenings for approximately an hour and were referred to as group meetings by EFR. During these meetings, the EFR team engaged in conversations about college experiences, inclusion, friendships, and various topics in members' current lives. While the purpose of these meetings included data collection, it was equally important to build relationships and rapport and foster a community. Semi-structured protocols (Appendix) were used to guide these discussions initially during the first three meetings, and EFR co-researchers were invited to lead future discussions. Interested co-researchers signed up for specific dates to lead group meetings, and developed questions to guide their discussions. As the PI, this author provided support during co-researcher-led meetings as needed (e.g., providing clarifying language, repeating questions, offering alternative response options, prompting participation) or when requested by a co-researcher (e.g., Can you share your screen so I can see our notes? Can you tell me what is written in the chat?).

Individual Interviews

Individual interviews between the PI and co-researchers took place throughout the study as a means of primary data collection. These interviews lasted approximately 30 minutes in length, and followed a semi-structured interview protocol about individual experiences and memories of college related to feelings of inclusion, exclusion, and relationships. The protocol was also PI-developed and purposely designed to be flexible

(e.g., order of questions could change, new topics could be introduced, questions could be omitted). Additionally, concise and concrete language was used. Individual interviews were used for relationship building, story sharing, and as an ongoing check-in with co-researchers between group meetings. During each interview, general pleasantries and greetings were exchanged (e.g., “How was the weekend?” “Did anyone else watch *The Bachelor*?”) followed by guided discussion from the interview protocol. All co-researchers participated in at least one individual interview, and many requested additional one-on-one meetings throughout the study to continue to share stories and generate new ideas for the direction of the research.

Visual Data Interviews

Visual data interviews following an adapted Photovoice process were an additional component of data collection. EFR co-researchers were asked to locate or produce a photograph which represented “inclusion,” or answered various discussion prompts (e.g., What is your dream home? If you were in charge, what would college be like?). Visual data were shared during group meetings or in one-on-one interviews depending on co-researcher preference, and the following questions guided discussions of the data: (a) What can we see? (b) What is happening in the image? (c) Why is this important for inclusion? (d) What memories do you have about this? and (e) What can this teach about inclusion? The full protocol can be found in the Appendix. The visual data interviews served as data collection and also analysis, as co-researchers discussed stories and meanings behind their images. Figure 1 is an example of a visual representation of Ann’s dream home.



Note. An example of visual data shared by an Everyday Friends Research Group (EFR) member who presented a dream home: “My dream home is like where I live now. And in my dream home I live with my husband and kids. I have a garden next to a big house and lots of flowers.”

Figure 1

Visual Data Example

Data Analysis

Data analysis followed a qualitative, phenomenological approach and was influenced by Collins’s (1992) conceptualization of a holistic research process as well as participatory ideology of disability movements of “nothing about us without us” (Charlton, 1998). Data analysis, like data collection and study design, remained fluid, and dependent on EFR member input (e.g., retelling or summarizing stories as means to interpret stories, preferring to discuss in a group and retell stories as means to generate themes).

Researcher Analysis and Initial Coding

Analysis followed a thematic process. First, the PI performed open-stage coding in which codes are formed by reviewing participants' vocabulary, expressions, and input to develop potential categories for group discussion (e.g., emotions, places, people, situations). Next, the PI generated a list of interesting themes based on the categories from interview and discussion data that would potentially turn into overarching themes in group analysis (the PI waited to formalize analysis of data until group analysis). Primary analysis followed during the group work stage, where initial interpretations (the PI's) were shared with co-researchers and the PI and the EFR team co-constructed themes and the emerging recommendations together.

Group Analysis

Group analysis work took place over three meeting sessions. This analysis was participatory and the PI served as co-facilitator to support co-researcher understanding and participation/access (e.g., modeling identifying repetitive refrains, emotions, categories) in describing emerging themes. During group analysis, clips of meetings and accompanying transcripts were shared (with permission from co-researchers) for all co-researchers to read and listen to in order to become familiar with the data (Creswell & Poth, 2018). Preliminary interpretations (PI-generated categories) were also shared with the EFR team and were based on thematic analysis of exact words, phrases, and emotions shared by EFR members (Reissman, 2008). Visual data sources (photographs, word clouds, drawings) were also shared. Figure 2 shows a word cloud developed during a

discussion to better understand the word *belonging*, as it was often used to describe inclusion.

What does belonging mean?



Note. Word cloud generated by Everyday Friends Research Group (EFR) words and phrases associated with “belonging.”

Figure 2

Word Cloud as Visual Data

Following each portion of data reviewed, the research team engaged in analysis through the following steps: (a) sharing words or phrases that seem important to them, (b) agreeing or disagreeing with statements in the data or from team members’ analysis, and (c) discussing data using the phrases “This person is saying ___ is important,” and “This [concept, emotion, story] can teach about inclusion because ___.” Co-researchers discussed the potential categories developed/identified during initial coding, and read through data to find new categories, and to confirm or contradict existing categories (e.g., wanting to be independent versus wanting to choose help). During discussions, pieces of

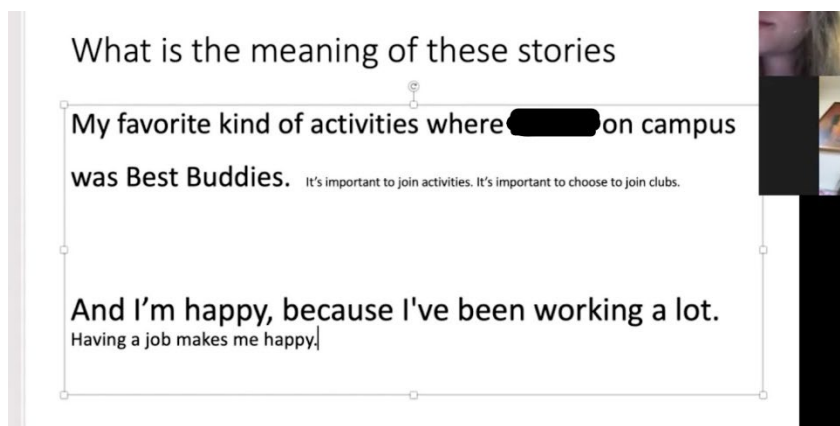
data were shown (see Figures 3 and 4) and co-researchers' analyses and summaries were written next to the data pieces (e.g., "I like choosing," "Inclusion is making choices").

| | | | |
|---|--------------------------------------|---|--|
| <p>I think it's because I am more independent, that I am now, and I have been making a lot of new friends being included a lot in doing Special Olympics. I love doing different inclusion meetings that I like to do, setting goals for ourselves. That's how I feel inclusion means to me, because I just want everybody or everyone to know about me being included and maybe we should help them.</p> | <p>Inclusion is important to me.</p> | <p>I like to do activities</p> | <p>Part of inclusion is making my own choices.</p> |
| <p>I just did a little drawing of at lunch. Here are people and then that's me. Then one of the people at the table says "You can sit with us." I can sit with them.</p> | | <p>I like choosing my friends and what I do</p> | |

Note. An example of one analysis procedure. A table containing two pieces of transcription data is displayed in the lefthand column and EFR members' summary or analysis statements are in the spaces to the right.

Figure 3

Screenshot of Data Analysis Discsuion



Note. An example of one analysis procedure: A sentence of transcript data is displayed and Everyday Friends Research Group (EFR) members' analysis statements are below.

Figure 4

Screenshot of Meaning-Making from Stories

The major theme of choice emerged as significant to all team members, and as a result the team developed recommendations for choice throughout their analysis.

Findings

The purpose of this study was to understand recommendations for positive inclusive experiences at the postsecondary setting from the perspectives of young adults with IDD who completed an IPSE through collaborative and participatory inquiry. Three recommendations emerged from the collaborative data analysis of choice.

When providing recommendations and suggestions for positive inclusive experiences at the PSE level, the research group discussed courses and classwork, the role of IPSE staff and support, and the importance of activities and friends, almost exclusively. Regardless of the topic being discussed, the top recommendation for positive experiences was to allow and honor choice. Within the theme of choice, there were three

major areas that the research team posed as recommendations: (a) choice in classes: what and where, (b) choice with help and support, (c) choice in friends and activities.

Recommendation 1: Keep Access Open But We Choose When, Where, and Who

Choice surrounding what courses to take and whom to take courses with was a topic discussed by all group members. Some co-researchers shared their preferences for course choice, while others shared experiences that did not offer choice and how that impacted them. However, all maintained that the opportunity to choose courses and settings when possible was essential for college inclusion. Veronica and Mary shared that choosing which courses to take in the university class setting was important to them, and they felt included when they could choose. Veronica shared about her university courses (regarding a course offered to all degree-seeking students in the university setting),

I had a lot of positive feelings about my [university] classes. I have taken so many [university] theater classes, that is part of my major [concentration of courses while at IPSE] and is perfect for me. It's all what I was choosing to study—this is perfect.

She also elaborated on her ideas for a dream college which included programs for students with disabilities like an IPSE that included the choice to take classes of interest with and without students with disabilities. Veronica explained getting to choose courses that interested her was important because they would support her getting a job in the future: “to have people with disabilities find a job of their interest from what they studied in college. Based on their favorite subject in school.”

Choosing courses based on the topic and content, as well as the setting or whom they want to be surrounded by in class (choosing based on friends being in the course) was another recommendation. Mary's positive experience with inclusion was a result of advocating and choosing the classes she wanted to take, and then "being granted" access to those classes by the IPSE staff and university faculty:

I felt included when I spoke up for myself and audited two or three regular classes outside the program where I did public speaking and communication classes and they [students in the class] listened. I loved those classes a lot and I passed [them].

Yahya shared that choosing to participate in his university course led to feeling included as well as developing friendships with students outside of the IPSE program:

I took Arabic classes. It was amazing [*sic*] class. [It's] Really fun sometimes and I know this guy, he lives in [Kuwait] and he's one of the best guy [*sic*]. Now he's married with [*sic*] one of my best friends. We go way back from that class and he would teach me Arabic.

Conversely, Teddy's recommendation for positive experiences with choice and access to courses focused on the physical setting and people in the class, not the topic. Teddy shared, "I don't like the [university] classes that you just sit there and they're talking all the time...it's just hard to kind of listen and remember stuff. The teachers talk the whole class so you're not really saying much." When asked how to improve the experience, he said having friends in class could help, but "they [IPSE staff] don't do that because they don't want the people [any student] to get distracted. Did it one year and

then they didn't like it because people [students] were getting distracted [with one another]." Rikki also shared that positive inclusive experiences were linked to the choice of staying in classes within the IPSE program, and not the university courses, because she was able to be comfortable when learning, "Meeting new friends at the school in [IPSE] classes, that's how I met [my boyfriend]." Rikki preferred the IPSE program classes and chose to participate in these over university courses because "The teachers know about that [seizure disorder and protocol] and they know what to do." She also shared that in university courses "I'm just shy with the people and alone." Mary recommended that IPSEs offer more course choices and programming such as activities, and clubs designed for students with and without disabilities for students to choose from. Additionally, she shared her hope for an increase in programs for students with IDD on college campuses with or without IPSEs,

Try to open up and get some more programs on campus. There are new programs at other schools that are doing and they come up with new support and new programs to bring some options, or classrooms with people with disabilities.

Mary acknowledged that her IPSE was great, but that IPSEs should be common on all college campuses, and students can choose to participate, "the more opportunity, the better for everyone." She continued, "With all the schools that we have in the United States, I really wish that they could have some more activity programs and classes that are for people with disabilities."

Sophia and Veronica also recommended that increasing opportunities for everyone to take classes they are interested in or choose to participate in would lead to

inclusion in the college setting. Sophia said if she were in charge of an IPSE, “I would make it for everyone, not just people with disabilities. I would include everyone if they choose to [join],” and Veronica shared “college can be for everyone, like me, you, person [sic] with Down syndrome, people that like music, everyone!” Whether deciding based on the location, the content, or the people, the EFR team recommended providing and honoring choices for academic programming to support inclusive experiences.

Recommendation 2: Offer Help, Allow Us to Choose How We Receive

Honoring choices surrounding desired or requested help (e.g., form of support given, how often, level of intensity) was recommended by the EFR team. They indicated that, in order to feel included and have positive experiences with inclusion, individuals with disabilities may need help, but recommend that these students choose what form of help and support.

Help with School. When sharing what he would do if he were in charge of an IPSE, Teddy said he would “check up on students once in a while but not all the time” to make sure they were feeling included. Teddy paused, and rolled his eyes when sharing about IPSE staff being present at all social events, “they have to be there, just in case [according to IPSE policy]” with a shrug, indicating that while he understood the rule, he did not see the support as always necessary. For example, during fall semester welcome back events on campus for all students, IPSE staff attend alongside IPSE students for support, but Teddy shared “I didn’t really need help to go walk around and stuff.” Rikki also recommended having the option for students to ask for help instead of it automatically being provided by IPSE staff support throughout the day and during events

at the IPSE, “Try to get people to be in groups, try to get them to get along or just make friends. Kind of like they ask for help if they need it and sometimes do it by themselves.” Similarly, Mary and Lara preferred having help in the program and university courses, and recommended that help be available for students if they need it, when they ask. Lara said there should be “a personal aide for people who need the help the most [in classes],” but not all of the time, “just help us when we need it.” At one point Sophia somewhat dryly added, “well yeah of course I need help, like everyone does sometimes. That's what teachers are there for”

Help with Friends and Leisure. Providing help with scheduling activities, attending events, spending leisure time, or fostering friendships was another recommendation that emerged from discussions. Teddy shared that he felt left out without a schedule, and recommended IPSE staff support to develop friendships and initiate group outings for students, “Times like you just sit in your dorm, kind of not sure what you want to do. Those are the times that just feel very, I don't know, left out or something.” He later added, “Sometimes by myself I was not feeling inclusion. I don't know. Just after classes, people all kind of want to do their own thing for awhile.” When Teddy was asked what could make this better, he explained he needed help to feel included, “Try and just plan things...I would try to be happy. Maybe get help trying to plan things with friends before you all go on your own way.” Yahya shared a favorite memory from college was an IPSE-sponsored trip to a downtown for a major league sporting game, and Lara added in the chat, “I remember that. It was cool 'cause I got to ride the [public transportation] with the teachers [IPSE staff].”

When responding to the discussion prompt “What are some things your dream college would have?” all EFR team members shared the importance of having help and/or a support system. Teddy shared that having a safe space designated for him/the program was important, and helped him feel comfortable and included. He shared the building with the IPSE courses was a place he could call his own and talk with friends. Ann also shared that a dream college would “help students reach their hopes and dreams.”

Help with Housing. EFR group members explained that inclusion within housing and community living situations works when there is help and support chosen by the students. Veronica recommended that living with someone without a disability can be helpful: “He is a housemate who drives, and makes sure he has a lot of money to get groceries because it’s important. And also learning how to cook which is important.” She recommended further that asking for help to live independently is beneficial,

What if a person like me, who has a disability needs help. If there’s a problem, one person with a disability and one person who is a mentor in the general population should together learn how to cook and do laundry, doing what is independently [*sic*] living which is very important.

Yahya also explained that it is important to choose whom he lives with if he wants to be included, but also that he knows having help is important: “I was thinking of getting a roommate, I’m not sure. Someone who can help me go to work on time, and with transportation, groceries, all that stuff are [*sic*] really important to me.”

EFR group members recommend that support and help offered in the home or dorm should be aligned with the individual's needs, not one-size-fits-all. Yahya shared that overbearing or unwanted support prevented him from feeling included in his campus housing, becoming upset and yelling about one staff member whom he wanted "to punch in the face" at times for enforcing rules about television and couch use in his off-campus housing. Yahya recommended staff members show respect to all people including students and let them live their life, "I'd want students to have fun...no dramas, give them respect, also let them have fun wherever they want."

Recommendation 3: Social Life and Activities Are Important, Let Us Choose

Choosing friendships and what activities to participate in with those friends was the topic discussed most frequently by all EFR group members. In order to have positive inclusive experiences, EFR group members shared that choosing whom to spend time with, and how to spend free time, were critical and choice needed to be offered and honored. For example, Rikki shared that the most important part of her inclusion experiences were her friends, "Meeting new friends, hanging out and people just be nice to each other," and that choosing friends is important because "I can hang out with people that might understand my disability and help me out with that." When asked about the top three favorite parts of college, Lara said, without hesitation, "all my friends and finding new friends" as number one.

Activities. When asked what he would do to promote inclusion if he were in charge of a college program, Teddy recommended the importance of choice in activities like "going to the movies, or mall, or just hanging out" so that "everybody has a chance

to do something.” Being able to choose how to spend time with friends was recommended by all EFR group members, and many shared positive experiences of feeling included when participating in chosen activities. “Best Buddies and drawing together, and Special Olympics together” were favorite activities of Ann and Mary, as well as Veronica who also shared that choosing to join these “communities” can help people make new friends and “get to know each other.” Due to negative experiences and memories, Veronica recommended that students should not only be allowed to choose what to participate in, but to be granted access regardless of disability or label. Watching her friend be prevented from participating in sorority recruitment and rushing due to the disability label and IPSE program affiliation per university student involvement was “really sad” and “hard.” A similar situation occurred with student government: Students from the IPSE program were not allowed to join and Veronica remembers that being “a big struggle.” Veronica bluntly and emphatically shared her recommendation with the research group, leaning into the camera and clasping her hands together: “include and allow people with disabilities to join!” One of Yahya’s favorite memories to share was the story of a weekend house party where alcohol was present, and as he shared, he paused, and held up his hands (to indicate “I’m innocent”), adding, “I don’t want to get in trouble...” (with a proud smirk) as he continued to talk about how fun the party was and how he was glad to choose to attend, despite not getting permission to do so from IPSE staff, indicating he remembers disobeying IPSE rules at that time.

Housing and Roommates. Reflecting on housing and roommate experiences led to discussions of choosing or having a say in shared housing and roommates. Lara shared

that she wished she could have lived on campus during her time at IPSE: “I didn’t get to [live in dorms] but if I could I would.” EFR group members discussed the dangers of living with an assigned roommate versus choosing whom to share space with. For example, Veronica shared that she was bullied by a roommate she did not choose and it was “pretty hard and intense.” Recommendations for choosing roommates emerged from stories similar to Veronica’s, negative experiences with roommates who had been assigned during freshman year. EFR members agreed that choosing one’s own roommates may prevent “drama” and “headaches.” Sophia bluntly added (with scoff), “I would choose to live alone, yes. Just me definitely.” Among the six members of the group who were still living in their family homes, all wanted to decide where to live next, and whom to live with. It was recommended that having “freedom” and living with friends would be fun without parents or anyone “bothering” them.

Discussion

The purpose of this research was to further investigate perspectives of inclusion at college (building from Manuscript 1) from individuals with IDD through recommendations for inclusive experiences. This work argues that it is not enough to only gather experiences and stories from a group of people with firsthand knowledge and expertise. These experiences are often reported; however, recommendations are made from the researcher, or assumed from the reader. In order to acknowledge participation and value research which includes this population, documentation should not stop at experiences and should include recommendations from those who have lived through the phenomena. These recommendations are bigger than “feeling inclusion,” and speak

directly to human rights and autonomy in response to ableist practices such as leaving individuals with IDD out of research or informing policy that continues to be knowingly and unknowingly upheld (de Haas et al., 2022). The recommendation for choice as an avenue to inclusion resonates with the joint position statement on inclusion utilized throughout this study:

Adults should have relationships of their own **choosing with individuals in the community**. Adults should live in a home **where and with whom they choose**.

Adults should engage in meaningful work in an inclusive setting and enjoy the same activities that are available to the general public [emphasis added].

(AAIDD, 2020)

The importance of choice for young adults has long been recommended during the period of transition to college (Nagaoka et al., 2015). Additionally, the opportunity for choice supports social inclusion of individuals in community settings (Amado et al., 2013; Hall, 2017). What this work adds is the recommendation for choice directly from individuals with IDD through conversations and storytelling, not pointed interviews. The interview protocols and data collection tools used in this study did not specifically focus on choice: It emerged through storytelling, sharing ideals and dreams, and making recommendations. According to EFR group recommendations, choice leads to positive inclusive experiences. Self-determination, independence, and autonomy are critical to postschool success (Bigby et al., 2019; Shogren & Wehmeyer, 2015), but within IPSE programs like the one most often discussed within the group, choice is not always offered or honored due to programming constraints created by the university or IPSE

administration (e.g., communication and safety policies, check-out forms for leaving dorms, mandatory attendance in courses), university rules, and student–family expectations (Francis et al., 2018, Plotner & Marshall, 2015).

The importance of choice in course enrollment was illuminating in a few ways. First, EFR co-researchers shared the importance of simply *having* a choice in which courses to participate in was critical for self-advocacy and feeling included in the college experience. Next, choice of course depended on two primary factors: (a) the content or course subject and (b) the setting of the course or potential peers (e.g., university courses or IPSE self-contained courses). Allowing for and honoring choice not only mirrors the degree-seeking experience (e.g., choosing a program of study) which is a goal for IPSEs (Flexer et al., 2021; Uditsky & Hughson, 2012), but explicitly shifts the control to the student. Many young adults with IDD transition to IPSEs with little-to-no experience in advocating for or directing their educational options (e.g., teachers and parents developed goals and courses for students through IEPs).

Co-researchers discussed positive experiences in university courses related to their interests. Yahya chose to participate in an Arabic class and, as a result, made lifelong friends. Mary’s story of advocating to participate in courses outside of the IPSE program made her feel proud and included in her own educational programming. Prior to Mary speaking up, she had not been afforded the opportunity from IPSE staff or university faculty for exposure to new content areas, or to meet nondisabled undergraduate peers. For Veronica, choosing her university courses (theater, music) based on interest and future career goal (theater teacher) was critical to feeling included

at college: Her enrollment had a purpose and was driven by her choices. One primary purpose of college is to pursue an education in a chosen field of study (major, minor, degree). IPSEs mirroring the degree-seeking experience should be promoting/requiring/ following student choices for which subjects to pursue. Conversely, the discussion of choosing no university courses needs to be considered. Rikki shared her preference was towards IPSE courses, and she did not have a strong desire to participate in university courses. Rikki did attend the courses, and had a say in the topics; however, she felt “lonely” and did not associate those experiences with inclusion. In fact, many EFR group members shared that they enjoyed and preferred IPSE courses. Contradicting many beliefs that general population access is the sole goal for inclusive experiences (Kauffman et al., 2020; Slee, 2019), co-researchers shared that inclusion is when you feel like you belong, and for many team members, that was felt most while in classes with students similar to them. This is in conflict with CTP requirements for inclusion (e.g., 50% of time at college alongside peers without disabilities; HEOA, 2008), and continues the discussion that quantifying inclusion with time and physical space cannot guarantee someone feeling included, and perhaps should focus more on the goals or needs of individual students.

The importance of choice in activities and friends also resonated throughout EFR team discussions. Similar to course selection, co-researchers stressed the importance of being able to choose what to participate in, when to do so, and with whom. College is a time to explore interests, develop new passions, and build relationships (Francis et al., 2017). Extracurricular activities such as college clubs, campus events, and Greek life

were among those most often discussed between the research team. Specifically, having their choices to participate (or not) *honored* with permission or access was a clear recommendation.

Veronica's story of being prevented from rushing Greek life by university student involvement illuminated discrepancies between an inclusive program and full campus access. IPSEs can be marketed as providing "the full college experience" but when recreation or leisure time choices are not provided or honored, a large portion of the college experience is left out. Similarly, Veronica's decision to audition for and join the university pep band and subsequent access *granted* highlights the same discrepancies and begs the question, to what extent is a program inclusive when gatekeepers across a college campus grant or permit choices to join clubs? Teddy, Ann, and Lara shared remembering the excitement of attending the men's basketball games and sitting in the student section alongside university peers cheering as well as tailgating outside of the arena, a favorite chosen activity.

Yahya's choice to attend the house party serving alcohol was one of his favorite memories of college, though according to program policy that was the "wrong" choice. This was an outlier, but equally a critical story shared as it highlighted the importance of the full college experience—including parties and drinking—which is not always accessible for students with IDD at IPSEs. Yahya choosing to ignore program rules resulted in a fun, inclusive, and memorable event.

According to participants, organizations and activities that are specifically for individuals with disabilities (Special Olympics, IPSE-sponsored clubs, Best Buddies),

while exclusive (i.e., developed for individuals with IDD), offer the experience of inclusion when chosen by individuals with IDD. Every co-researcher described a positive experience with inclusion within organizations designed for individuals with IDD, indicating that the feeling of belonging is more important than the heterogeneity of an environment. Choosing activities was just as important as choosing whom to be with also related to the people present.

Choosing whom to be around, build relationships with, and whom to live with was another clear recommendation. For many students with IDD, access to preferred peers is inappropriately or disproportionately controlled by professionals or families (e.g., placement in classes, opportunity to meet others, lack of programming; Agran et al., 2020; Kauffman et al., 2020; Maciver et al., 2019), and at college, the increased freedom and autonomy can afford individuals with IDD increased choices.

Rikki shared that it was important to choose where she ate and whom she sat with on campus, and that it was disappointing when those choices were not honored and she could not sit with preferred friends due to mandatory IPSE schedules or IPSE staff instructing her to branch out and meet other people: “I felt kind of disappointed and bad because they’re my closest friends.”

Not unlike other college students, EFR co-researchers had varied experiences with roommates. Teddy’s overall positive experience with roommates led to him choosing to live with them postcollege. Veronica had a negative experience with an assigned roommate, and lack of choice resulted in conflict and the lack of feeling inclusion. Mary shared about her current living arrangements and eagerness to get out of

her family's house, whereas Ann prefers to live with family (both during the time at IPSE and after program completion). The resounding recommendation is for students to choose their roommates.

Last, the importance of choice in help was often discussed. EFR team members shared that they expected and preferred to have some type of help, and that they would like to choose the form and frequency or intensity. What was most notable was the dichotomy of wanting independence and freedom while acknowledging needing or expecting help, especially in university courses, when attempting to join clubs, or within dorms. No team member recommended total freedom or independence, and in fact acknowledged the importance of having support from family and paid personnel. When describing independence with help, everyone recommended *having* choices. This is a straightforward and practical recommendation, and one considered a best practice across instructional settings (e.g., providing choice in assignments or activities; CAST, 2018). Additionally, this speaks to the expertise of the researchers and should serve as an example of the importance of trusting and listening to students and individuals with IDD. Successful college experiences require a network of people and help including peer mentors and paid support staff (Carter & Bumble, 2018). In fact, one of the greatest forms of support for students' inclusive experiences in college are peer mentors (Carter et al., 2019; Hafner et al., 2011) and EFR team members recommended having this help, but being able to choose how or when to use it.

The shift of staff from supervisors to an advisor or mentor is one of the common transitions experienced by college students as they learn to reach out for help as needed

(e.g., academic advisor instead of guidance counselor or case manager). EFR members described relying on IPSE staff as mentors or facilitators (e.g., helping to organize an activity, assisting with errands, peer mentorship), but not as a case manager or supervisor. The group collectively agreed that all people have areas where help is needed, and recommended IPSE staff collaborate *with* students to offer the help or fade it as needed. It seems this recommendation should be second nature as IPSEs are not extensions of high school and are intended to promote independence and self-determination (Francis et al., 2018; Rooney-Kron et al., 2022), yet many EFR members struggled in receiving the right level of support because their choices were not heard or honored.

Implications for Practice

What this work shows is that because of federal initiatives such as the Higher Education Opportunity Act's development of model programming (2008), there has been a shift in understanding of "what can be" for individuals with IDD, but also "what should be." It seems that, without a federal mandate for inclusion with typically developing peers, young adults on college campuses should be able to decide and define what inclusion looks like in their lives, whom they are with, and how they are accessing environments such as the classroom or housing. Both conceptualizations should be informed directly by individuals with IDD, either solely or alongside decision makers and people in positions of power at the university level. Simply put, if the collective belief is that attending college is becoming common, then the voice of students with IDD is needed to share and inform about the college experience as well as recommendations and strategies for success. This study offers implications for practice at the postsecondary

setting as well as in elementary and secondary settings. EFR co-researchers offered recommendations for choice to increase inclusive programming and opportunities for inclusion in college.

Professionals or Staff. Programs and professionals should consider choice at every level of their program: where it exists, where it is forced, and where or when it is honored and ignored. Supported decision-making models may provide programs a place to start when providing choices (Supported Decision Making Inventory System, Shogren et al., 2017; LifeCourse, Curators of the University of Missouri, 2020; Flexer et al., 2021), especially if choices in courses, activities, roommates, or scheduling have not previously been offered. In order to expand social and leisure skills, students at IPSEs need to be able to choose how to spend their time, and program leadership should cultivate relationships with campus organizations and offices to facilitate students with IDD joining traditional clubs and organizations outside of an IPSE. Further, programs should also honor the choice to say no, or stop (e.g., Rikki not wanting to take university courses) and the opportunity to make the “wrong” choice.

College settings should not be the first opportunity for choice. Professionals working with elementary and secondary students should be explicitly teaching and naming choice (including nonexamples or forced choice) across domains to prepare for the future. Students should not be in college or preparing to transition before realizing they can decide whom to spend time with, what subjects to favor, where they want to live in the future. Person-centered planning protocols (e.g., LifeCourse, Curators of the University of Missouri, 2020; *Person-Centered Planning: PATH, MAPS, and Circles of*

Support, n.d.) can support teams in preparing students to advocate and make decisions for and about their lives.

Failing and making mistakes is equally important to the learning and development process as is succeeding. IPSEs need to consider allowing choice and the accompanying risk in order to support the learning process through mistakes. Frameworks such as the dignity of risk (Bumble et al., 2022) should be utilized when providing and honoring choices or preparing individual or program plans as it specifically recognizes the importance of risk as an opportunity for growth and learning.

Last, IPSE leadership should consider the role of individuals with IDD on advisory or policy panels and alumni programs/networks. Recommendations such as these from the EFR team could be shared with prospective students and families during information sessions to show the spectrum of possibilities at college. Current policies may need to be adjusted or developed in response to recommendations (e.g., scope and sequence of support, communication policies, academic requirements) alongside the federal guidelines for IPSE programming.

Students. A major implication for practice is that students should receive instruction and encouragement to regularly advocate for choice and continue to make decisions in their lives. If choices do not seem available, students need to speak up and ask for what they want, just as Mary did. Students may seek mentors within the IPSE with disabilities, join self-advocacy groups, or request meetings with IPSE staff or faculty. Making choices—even the wrong ones—is part of young adulthood and being human.

Limitations

There are four primary limitations of this study. First, the participatory design may have impacted the stories shared and in turn data collected. The methodological decision to only gather data from individuals with IDD and not other stakeholders may be seen as a limitation, particularly when considering the rise of IPSEs and number of additional stakeholders making decisions in transition to college for students with IDD. However, the distrust of individuals with disabilities in research has unfairly resulted in this ableist limitation (e.g., requiring proxies to validate data, distrust of a shared experience due to perceived cognitive limitation). Participatory design with individuals with IDD is commonly critiqued due to the challenges associated with power dynamics (e.g., the PI forcing or influencing participants to join or acquiesce) as well as questioning the degree to which the study is “participatory” (Hammel et al., 2008; Nind & Vinha, 2014). EFR co-researchers chose how they participated throughout this study including what or how much they shared during interviews and group analysis. A formal structured protocol and specific expectations for participation may have resulted in more data. Analysis loosely followed thematic steps (e.g., codes, categories, themes), but in the commitment to accessibility and co-researcher-generated work, textbook approaches were not followed, which is another limitation.

Second, the virtual meeting format due to COVID-19 was also a limitation, as it prevented community-building opportunities in person, and required a presumed level of ability and independence of participants (e.g., navigating the computer, accessing Zoom software, managing the chatbox function). Third, the length of the study and number of

group meetings was a limitation. While the group discussion came to a close based on co-researcher input and lack of motivation to continue discussions, more time spent in conversation could have provided additional information.

Last, although not a goal of qualitative research, especially participatory and phenomenological inquiry, this study only focused on stories of eight individuals and cannot be generalizable.

Implications for Future Research

The limited research including individuals with IDD that exists is promising, but should continue to be examined, critiqued, and expanded upon to build a field that is inclusive and more equitable. Future research on IPSE experiences should continue to seek out the expert—the individual with IDD—and in the spirit of inclusion and access, student input should be determining the trajectory of postsecondary academic programming. The importance of choice in this work suggests research focusing on choice, and supported decision making may impact transition and postschool outcomes. Particularly research aimed at developing supported decision-making protocols or processes, and the opportunity to build in choice throughout a day/across settings, is needed.

Research focused on independent living outcomes post-IPSE should investigate the long-term perspectives of inclusion for individuals with IDD who completed an IPSE program. Exploring where IPSE alumni live and with whom, as well as how they decided on their living arrangements, can provide recommendations or programming guidelines for IPSEs as they educate, support, and prepare young adults to enter communities.

The concept of dignity of risk and failing (or making the wrong choice) needs to be further investigated across IPSEs. Research on providing help or support within a framework such as dignity of risk (Rooney-Kron et al., 2022) can investigate choice as it relates to risk and safety within a program or a campus. Identifying levels of risk across a continuum (e.g., manufactured with forced choice or authentic with full autonomy; Bumble et al., 2022) and the threshold for success, failure, and safety management can considerably support growth and development of individual students at an IPSE as well as programmatic expectations and philosophy. Similarly, future research should consider an appreciative inquiry approach and explore or investigate programs for individuals with IDD (IPSE or otherwise, including high school and transition programs) which provide choice and choice-making across settings. This may provide additional goals and guidelines for IPSE programs with respect to what is working and what new actions need to be taken. Additionally, future research should take an inclusive research approach and learn about choice-making directly from individuals with IDD.

Last, this study should be revisited to identify power dynamics and imbalances which may impact the findings and methodological rigor of the study. Through critical analytic memoing and coding, the data and conversations from this study may be reexamined to uncover or highlight when or where researcher positionality impacted the meaning-making among the EFR group. With tools such as reconstructive horizon analysis (RHA; Carspecken, 1996), this work and researcher engagement could be examined for deeper reflexivity and better understanding of power issues (Call-

Cummings & Ross, 2019), which may strengthen future research processes with EFR groups.

Appendix for Second Manuscript

Semi-Structured Individual Interview/Conversation

Thank you so much for meeting with me today. I will be recording this conversation so that I can remember what we talk about, and we can go back and watch it together anytime you want. If you ever want to take a break or stop talking, that's just fine. Does that make sense?

Great let's get started!

So I already know a little bit about you, like _____ (draw from personal relationship and background knowledge) but let's start by learning a little more!

- *Where from/age/family/current living situation*
- *What PSE did you attend? When?*

Like I said in our group meeting, and in my emails/FB messages, I am really excited to work with you and listen to your stories/experiences! I know I have shared with you that I'm interested in inclusion, but I also want to learn about your time at the PSE program and what life is like now! Reed: I want to talk about your time at [Program Name] today. When did you attend the program?

Can you tell me why you wanted to come to the program?

What are some things you liked about the program? What are some things you didn't like?

I am a teacher, and I used to work at a program just like this one. We always talked about inclusion. Have you heard of that word before? Where? Who uses it? Do you hear it now that you are out of school?

When you hear the word inclusion, what do you think of? Can you tell me the definition of inclusion? What do you think inclusion means? What does it mean in school? College?

Back up plan: Okay, what if we call inclusion this _____.

Tell me about a time you felt inclusion at [Program name]

- *Can you tell me about who you were with?*
- *Can you tell me about what you were doing?*
- *Can you tell me about how you were feeling?*

Tell me about a time you didn't feel inclusion at [Program name] What did you not get to do? What could you change?

- *Can you tell me about who you were with?*
- *Can you tell me about what you were doing?*
- *Can you tell me about how you were feeling?*
- *How could you make that better?*

Now I'd love to talk about your life now, after [Program name]!

- *Where are you living? Who with? Tell me a little about your living situation.*
- *Tell me about your employment/job experience. Do you have a job?*
- *What do you do in your spare time? Who do you spend time with?*

When do you feel inclusion now?

Are there times you don't feel inclusion?

If you were in charge of [Program name], what would you do about inclusion?

Do you have suggestions for your [Program director name] or teachers?

Semi-Structured Individual Interview/Conversation II

Thank you so much for meeting with me today. I will be recording this conversation so that I can remember what we talk about, and we can go back and watch it together anytime you want. If you ever want to take a break or stop talking, that's just fine. Does that make sense?

Great let's get started!

So the last time we talked just the two of us we talked about... (review based on notes)

- *What was your favorite part of our discussion?*
- *Anything you didn't like?*

I'm hoping we can dive a little deeper into stories about inclusion today, are you okay with that?

Review purpose of study: You recently completed a college program designed for individuals with disability, I want to hear about your experiences

What were some things you liked about the program? What are some things you didn't like?

When you hear the word inclusion, what do you think of? Can you tell me the definition of inclusion? What do you think inclusion means? What does it mean in school? College?

Last time you mentioned feeling inclusion at _____.

- *Do you have any other memories from that time or that day?*
- *How did you end up at _____ (time/place)*

Is there another time you felt inclusion?

- *Who were you with? What were you doing? Can you tell me about how you were feeling?*

You also shared about _____ when you didn't feel inclusion

- *Do you have any other memories from that time or day?*
- *How did you end up at _____ (time/place)*

Now I'd love to hear how you are feeling with the research group. Any suggestions?

Recommendations?

- *What is your favorite part of our research group?*
- *Least favorite?*
- *Do you want to talk about anything in our next meeting?*
- *What should we do with our work together?*
 - *Do you want to keep meeting?*

Semi-Structured Individual Interview or Group Conversation III

Thank you so much for meeting with me today. I will be recording this conversation so that I can remember what we talk about, and we can go back and watch it together anytime you want. If you ever want to take a break or stop talking, that's just fine. Does that make sense?

Great let's get started!

So I already know a little bit about you, like _____ (draw from personal relationship and what learned so far in study) but let's review a little

- *How are you feeling so far about our research group?*
- *Is there anything you want to talk about today?*

Today we will review a little from our group talks, and also talk about Dream College and Dream Living. We can also talk about things you want.

Can you tell/show me your Dream College ideas?

- *Can you tell me more about (classes/friends/housing)*
- *What is the most important part?*
- *Why did you pick _____ (location, classes, friends)*

Can you tell/show me your Dream Living?

- *Can you tell me more about (roommate, family, pet)*
- *Why did you pick (location, roommate)*
- *You mentioned _____ (detail), it sounds like _____ is important. Can you share more?*

Tell me about what you feel or think when you hear Inclusion

- *Do you want to add anything?*
- *If positive: Can you tell me a story about a [positive word they used]*
- *If negative: Can you tell me a story about a [negative word they used]*

Now I'd love to talk about our research together, and hear ideas!

- *What is your favorite part of our research group?*
- *Least favorite?*
- *Do you want to talk about anything in our next meeting?*
- *What should we do with our work together?*
 - *Do you want to keep meeting?*

Semi-Structured Initial Group Protocol

Schedule group Zoom meeting at a time where all # participants can attend, plan for 1hr of meeting time.

Thanks everyone so much for meeting with me today. I will be recording this conversation so that I can remember what we talk about, and we can go back and watch it anytime! The video will be private though, only the people on this call can see or hear it. If you ever want to take a break or stop talking, that's just fine. You also can turn your camera off too, so that just your voice is being recorded! Does that make sense?

ICEBREAKER

Great let's start with some introductions! How about everyone starts with introducing yourselves—tell us the name you want us to call you, what program or college you went to after high school, where you live now, and one happy thought! I'll go first. My name is Sascha, after high school I went to college in California and now I'm in school at George Mason. I live in Ashburn, Virginia now, and one thing I am happy about right now is _____.

Prompt as needed to make sure all participants who want to participate are able to.

INTRODUCTION

Great to meet/see everyone! So I wanted us all to have a chance to meet and chat together before our project starts. All of you are on this call because you agreed to work on a project with me about learning about inclusion for young adults with disabilities. Today if it is okay with everyone I was hoping we could have a group meeting where we got to know each other better, or catch up with people we haven't seen in awhile. The spring/summer has been really crazy with COVID-19 and social distancing, so I wanted us to have a social zoom time right now. We can talk about inclusion, and college, but we can also just hang out and talk about whatever!

IF CONVERSATIONS DO NOT START NATURALLY, FOLLOWING PROMPTS WILL BE USED:

We can start with some questions or ideas about the project. Does anyone have any questions for me since I am the one who reached out to you about being a part of this project?

I am in school right now to become a researcher, and I'm really interested in special education, disability studies, inclusion, and working with people with disabilities. It is important to me that people with disabilities are a part of research.

- *Has anyone ever worked on a project like this?*

- *Been on a research team?*
 - *Experiences with research?*
- *Is anyone interested in doing research?*
- *What is important to know about people with disabilities/Inclusion/research*

Inclusion: *So I really want to learn about inclusion from everyone. What kind of questions should I ask about inclusion?* General conversation/topic probes

Who has roommates? What's great/not great about living situation?

Work? COVID-19 impact?

Special Olympics: no fall sports this year, how is Fitness Combine going?

Upcoming plans/Favorite summer stories/memories

Semi-Structured Group Protocol

To be used as facilitation of group discussions, as needed.

Thanks everyone so much for meeting again. I will be recording this conversation so that I can remember what we talk about, and we can go back and watch it anytime! The video will be private though, only the people on this call can see or hear it. If you ever want to take a break or stop talking, that's just fine. You also can turn your camera off too, so that just your voice is being recorded! Does that make sense?

ICEBREAKER/WELCOME/INTRODUCTION

Great to meet/see everyone again! The last time we met, we (review prior discussions)

Something I noticed was a lot of talk about ____ (modeling finding patterns or refrains)

Who else noticed anything about conversation

IF CONVERSATIONS DO NOT START NATURALLY, FOLLOWING PROMPTS CAN BE USED:

(Review as needed): I'm really interested in special education, disability studies, inclusion, and working with people with disabilities. It is important to me that people with disabilities are a part of research.

- *How is everyone feeling about our meetings and research so far?*
 - *Any feelings about being co-researchers/*
- *Does anyone have any new ideas or questions?*

Discussion prompts/starters:

I was wondering if ____ (all or one person) could share more about ____.

-Does anyone else want to add, or have another story?

Inclusive memories

Positive memories of courses, friends, activities, staff

-Favorite event on campus/Favorite event you went to during college

Wish I could have changed ____ (courses, friends, activities, staff, other)

-Negative feelings? Feeling left out

What is the most important thing to share about inclusion?

Concluding/checking in:

How does everyone feel about today's talk? About the group?

Do you want to meet again?

____ will lead the next meeting (as needed).

Semi-Structured Individual Interview/Conversation: Visual Analysis

SHOWeD Method (Wang and Burris' (1997) integration of Schaffer, 1983)

*What do you **See** here?*

*What is really **H**appening here?*

*How does this relate to **O**ur lives?*

***W**hy does this concern, situation, or strength exist?*

*How can we become **E**mpowered through our new understanding?*

*And, what can we **D**o?*

SHIMeT Protocol (adapted)

Thank you so much for meeting with me today. I will be recording this conversation so that I can remember what we talk about, and we can go back and watch it together anytime you want. If you ever want to take a break or stop talking, that's just fine. Does that make sense?

Great let's get started!

So today I would love to take a look at the photo or picture you want to share. We will be looking at it together on the screen.

Share screen/make image visible

*First, let's just talk about what we **See** here? (follow up probes/prompts as necessary)*

- *what/who is in the picture?*
- *What can we see? I see ...*

*Next, what was **H**appening in the picture?*

- *How did you get to ____?*
- *Why were you with ____?*
- *Who was taking the picture?*
- *What were you thinking about when you drew this (if photo)*

*What makes this **I**important for **I**nclusion?*

- *Why does this make you think of inclusion?*
- *What was inclusion in the photo?*

*What is the **M**emory behind this?*

- *What do you remember about this photo/place/person*
- *Do you remember how you were feeling?*
 - *How the others were feeling?*

*What can this **T**each or **T**ell us about inclusion?*

- *How can this help people learn about inclusion*
- *What else is inclusion here?*

Lastly: Any other reason you wanted to share this picture?

References for Second Manuscript

- Agran, M., Jackson, L., Kurth, J. A., Ryndak, D., Burnette, K., Jameson, M., Zagona, A., Fitzpatrick, H., & Wehmeyer, M. (2020). Why aren't students with severe disabilities being placed in general education classrooms: Examining the relations among classroom placement, learner outcomes, and other factors. *Research and Practice for Persons with Severe Disabilities*, 45(1), 4–13. <https://doi.org/10.1177/1540796919878134>
- Amado, A. N., Stancliffe, R. J., McCarron, M., & McCallion, P. (2013). Social inclusion and community participation of individuals with intellectual/developmental disabilities. *Intellectual and Developmental Disabilities*, 51(5), 360–375. <https://doi.org/10.1352/1934-9556-51.5.360>
- American Association on Intellectual and Developmental Disabilities. (2021). *Definition of intellectual disability*. <https://www.aaid.org/intellectual-disability/definition>
- American Association on Intellectual and Developmental Disabilities. (2020). *Inclusion: Joint position statement of AAIDD and the Arc*. <https://www.aaid.org/news-policy/policy/position-statements/inclusion>
- Avellone, L., Camden, J., Taylor, J., & Wehman, P. (2021). Employment outcomes for students with intellectual disabilities in postsecondary education programs: A scoping review. *Journal of Postsecondary Education and Disability* 34(3), 223–238. <https://files.eric.ed.gov/fulltext/EJ1325428.pdf>
- Bigby, C., Whiteside, M., & Douglas, J. (2019). Providing support for decision making to adults with intellectual disability: Perspectives of family members and workers in disability support services. *Journal of Intellectual and Developmental Disability*, 44(4), 396–409. <https://doi.org/10.3109/13668250.2017.1378873>
- Bumble, J. L., Worth, C. R. J., Athamanah, L. S., Rooney-Kron, M., Register, A., & Lidgus, J. (2022). “Messy inclusion”: A call for dignity of risk in inclusive postsecondary education. *Inclusive Practices*, 1(2), 64–69. <https://doi.org/10.1177/27324745211050023>
- Call-Cummings, M., & Ross, K. (2019). Re-positioning power and re-imagining reflexivity: Examining positionality and building validity through reconstructive horizon analysis. In K. K. Strunk & L. A. Locke (Eds.), *Research methods for*

- social justice and equity in education* (pp. 3–13). Palgrave Macmillan Cham.
<https://doi.org/10.1007/978-3-030-05900-2>
- CAST. (2018). *Universal design for learning guidelines version 2.2*.
<http://udlguidelines.cast.org>
- Carspecken, P. H. (1996). *Critical ethnography in educational research: A theoretical and practical guide*. Psychology Press.
- Carter, E. W., & Bumble, J. L. (2018). The promise and possibilities of community conversations: Expanding opportunities for people with disabilities. *Journal of Disability Policy Studies, 28*(4), 195–202.
<https://doi.org/10.1177/1044207317739408>
- Carter, E. W., Gustafson, J. R., Mackay, M. M., Martin, K. P., Parsley, M. V., Graves, J., Day, T. L., McCabe, L. E., Lazarz, H., McMillan, E. D., Schiro-Geist, C., Williams, M., Beeson, T., & Cayton, J. (2019). Motivations and expectations of peer mentors within inclusive higher education programs for students with intellectual disability. *Career Development and Transition for Exceptional Individuals, 42*(3), 168–178. <https://doi.org/10.1177/2165143418779989>
- Charlton, J. I. (1998). *Nothing about us without us: Disability, oppression and empowerment*. University of California Press.
<https://doi.org/10.1525/9780520925441>
- Collins, E. C. (1992). Qualitative research as art: Toward a holistic process. *Qualitative Issues in Educational Research, 31*(2), 181–188. <https://www-jstor-org.mutex.gmu.edu/stable/1476405>
- Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry and research design: Choosing among five approaches* (4th ed.). Sage
- Curators of the University of Missouri. (2020). *Charting the LifeCourse nexus*.
<https://www.lifecoursetools.com/>
- de Haas, C., Grace, J., Hope, J., & Nind, M. (2022). Doing research inclusively: Understanding what it means to do research with and alongside people with profound intellectual disabilities. *Social Sciences, 11*, 159.
<https://doi.org/10.3390/socsci11040159>
- Fals Borda, O., & Rahman, M. A. (1991). *Action and knowledge: Breaking the monopoly with participatory action-research*. Apex Press.

- Fine, M., & Torre, M. E. (2004). Re-membering exclusions: Participatory action research in public institutions. *Qualitative Research in Psychology, 1*, 15–37. <https://doi.org/10.1191/1478088704qp003oa>
- Flexer, R., Baer, R., & McMahan-Queen, R. (2022). Designing and implementing postsecondary education opportunities for students with intellectual disability: An illustration of quality, access, and inclusion. *Journal of Inclusive Postsecondary Education 3*(2). <https://doi.org/10.13021/jipe.2021.2940>
- Francis, G. L., Duke, J. M., & Chiu, C. (2017). The college road trip: Supporting college success for students with autism. *Division of Autism and Developmental Disabilities Online Journal, 4*, 20–35. http://daddcec.org/Portals/0/CEC/Autism_Disabilities/Research/Publications/DOJ_Volume4_2017.pdf
- Francis, G. L., Gordon, S., Kliethermes, A. J., Register, A., Baldini, D., & Grant, A. (2018). Developing and implementing a postsecondary education program for young adults with intellectual and developmental disabilities: Processes and procedure. *Teacher Educators' Journal, 11*, 134–156. <https://files.eric.ed.gov/fulltext/EJ1174734.pdf>
- Francis, G. L., Reed, A. S., & Howard, M. E. (2020). Interactions with and between families and professionals in college: Perspectives of young adults with intellectual and developmental disabilities. *Inclusion, 8*(2), 163–179. <https://doi.org/10.1352/2326-6988-8.2.163>
- Grigal, M., Hart, D., Papay, C., & Smith, F. (2018). *Year two program data summary (2016-2017) of the TPSID model demonstration projects*. University of Massachusetts Boston, Institute for Community Inclusion.
- Hafner, D., Moffat, C., & Kisa, N. (2011). Cutting-edge: Integrating students with intellectual and developmental disabilities into a 4-year liberal arts college. *Career Development for Exceptional Individuals, 34*, 18–30. <https://doi.org/10.1177/0885728811401018>
- Hall, S. A. (2017). Community involvement of young adults with intellectual disabilities: Their experiences and perspectives on inclusion. *Journal of Applied Research in Intellectual Disabilities, 30*(5), 859–871. <https://doi.org/10.1111/jar.12276>
- Hammel, J., Magasi, S., Heinemann, A., Whiteneck, G., Bogner, J., & Rodriguez, E. (2008). What does participation mean? An insider perspective from people with disabilities. *Disability and Rehabilitation, 30*(19), 1445–1460. <https://doi.org/10.1080/09638280701625534>
- Higher Education Opportunity Act, Pub. L. No. 110-315, 122 Stat. 3078 (2008).

- Kauffman, J. M., Travers, J. C., & Badar, J. (2020). Why some students with severe disabilities are not placed in general education. *Research and Practice for Persons with Severe Disabilities*, 45(1), 28–33. <https://doi.org/10.1177/1540796919893053>
- Kemmis, S., & McTaggart, R. (2007). Participatory action research: Communicative action and the public sphere. In N. D. Denzin & Y. S. Lincoln (Eds.), *Strategies of qualitative inquiry* (4th ed., pp. 271–330). SAGE.
- Kurth, J. A., & Mastergeorge, A. M. (2010). Individual education plan goals and services for adolescents with autism: Impact of age and educational setting. *The Journal of Special Education*, 44, 146–160. <https://doi.org/10.1177/0022466908329825>
- Lee, C. E., & Taylor, J. L. (2022). A review of the benefits and barriers to postsecondary education for students with intellectual and developmental disabilities. *The Journal of Special Education*, 55(4), 234–245. <https://doi.org/10.1177/00224669211013354>
- Lund, E. M., Hughes, R. B., McDonald, K. E., Leotti, S., Katz, M. R., Beers, L. M., & Nicolaidis, C. (2022). Creating academic–community partnerships to jointly enhance advocacy and research on violence and disability: Two case examples. *Psychological Trauma: Theory, Research, Practice, and Policy*, 14(6), 956–963. <https://psycnet.apa.org/doi/10.1037/tra0001135>
- Maciver, D., Rutherford, M., Arakelyan, S., Kramer, J. M., Richmond, J., Todorova, L., Romero-Ayuso, D., Nakamura-Thomas, H., Ten Velden, M., Finlayson, I., O'Hare, A., & Forsyth, K. (2019). Participation of children with disabilities in school: A realist systematic review of psychosocial and environmental factors. *Plos One*, 14. <https://doi.org/10.1371/journal.pone.0210511>
- Mazzotti V. L., Rowe, D. A., Kwiatek S., Voggt, A., Chang, W., Fowler, C. H., & Test, D. W. (2021). Secondary transition predictors of postschool success: An update to the research base. *Career Development and Transition for Exceptional Individuals*, 44(1), 47–64. <https://doi.org/10.1177/2165143420959793>
- McDonald, K. E., & Kidney, C. A. (2012). What is right? Ethics in intellectual disabilities research. *Journal of Policy and Practice in Intellectual Disabilities*, 9, 27–39. <https://doi.org/10.1111/j.1741-1130.2011.00319.x>
- Nagaoka, J., Farrington, C. A., Ehrlich, S. B., & Heath, R. D. (2015, June). Foundations for young adult success: A developmental framework [Concept paper]. The University of Chicago Consortium on Chicago School Research (Urban Education Institute).

- Neubert, D. A., Grigal, M. S., Moon, M., & Redd, V. (2001). Post-secondary educational practices for individuals with mental retardation and other significant disabilities: A review of the literature. *Journal of Vocational Rehabilitation, 16*(3–4), 155–168.
- Nind, M., & Vinha, H. (2014). Doing research inclusively: Bridges to multiple possibilities in inclusive research. *British Journal of Learning Disabilities, 42*(2), 102–109. <https://doi.org/10.1111/bld.12013>
- Paiewonsky, M. (2011). Hitting the reset button on education: Student reports on going to college. *Career Development for Exceptional Individuals, 34*(1), 31–44. <https://doi.org/10.1177/0885728811399277>
- Parisi, P., & Landau, J. (2019). Positive outcomes for students with intellectual disability attending college: Why medicaid waivers should provide support. *Think College Insight Brief, 43*. University of Massachusetts Boston, Institute for Community Inclusion.
- Patton, M. Q. (2015). *Qualitative research and evaluation methods* (4th ed.). Sage.
- Person-centered planning: PATH, MAPS, and circles of support*. (n.d.). Inclusion Press. <https://inclusion.com/path-maps-and-person-centered-planning/>
- Plotner, A. J., & Marshall, K. J. (2015). Postsecondary education programs for students with an intellectual disability: Facilitators and barriers to implementation. *Intellectual and Developmental Disabilities, 53*, 58–69. <https://doi.org/10.1352/1934-9556-53.1.58>
- Prohn, S. (2014). A grounded theory of social inclusion for postsecondary education students with intellectual disability (UMI No1 3690350) [Doctoral dissertation]. ProQuest Dissertations and Theses.
- Riessman, C. K. (2008). *Narrative methods for the human sciences*. Sage.
- Rooney-Kron, M., Regester, A., Lidgus, J., Worth, C., Bumble, J. L., & Athamanah, L. S. (2022). A conceptual framework for enabling risk in inclusive postsecondary education programs. *Inclusive Practices, 1*(3), 114–123. <https://doi.org/10.1177/27324745221078599>
- Schaffer, R. (1983). *Beyond the dispensary*. Nairobi: AMREF (The African Medical and Research Foundation).
- Shogren, K. A., & Wehmeyer, M. L. (2015). A framework for research and intervention design in supported decision-making. *Inclusion 3*, 17–23. <https://doi.org/10.1352/2326-6988-3.1.17>

- Shogren, K. A., Wehmeyer, M. L., Uyanik, H., & Heidrich, M. (2017). Development of the Supported Decision Making Inventory System. *Intellectual and Developmental Disabilities, 55*(6), 432–439. <https://doi.org/10.1352/1934-9556-55.6.432>.
- Slee, R. (2019). Belonging in an age of exclusion. *International Journal of Inclusive Education, 23*(9), 909–922. <https://doi.org/10.1080/13603116.2019.1602366>
- Strnadová, I., & Walmsley, J. (2018). Peer-reviewed articles on inclusive research: Do co-researchers with intellectual disabilities have a voice? *Journal of Applied Research in Intellectual Disabilities, 31*, 132–141. <https://doi.org/10.1111/jar.12378> .
- Think College National Coordinating Center Accreditation Workgroup. (2021). *Report on model accreditation standards for higher education programs for students with intellectual disability: Progress on the path to education, employment, and community living*. University of Massachusetts Boston, Institute for Community Inclusion.
- Uditsky, B., & Hughson, E. (2012). Inclusive postsecondary education—An evidence-based moral imperative. *Journal of Policy and Practice in Intellectual Disabilities 9*(4), 298–302. <https://doi.org.10.1111/jppi.12005>
- Walte, S., Cushing, L. S., Athamanah, L. S., & Posey, K. (2017). Seeking the perspectives of transition-age students with significant disabilities in research since 1990. *Division on Autism and Developmental Disabilities Online Journal, 4*, 47–62.
- Wang, C. C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior, 24*(3), 369–387. https://doi.org.10.1177_109019819702400309
- Whirley, M. L., Gilson, C. B., & Gushanas, C. M. (2020). Postsecondary education programs on college campuses supporting adults with intellectual and developmental disabilities in the literature: A scoping review. *Career Development and Transition for Exceptional Individuals, 43*(4), 195–208. <https://doi.org/10.1177/2165143420929655>

A Reflection on Inclusive Research

Abstract

This self-study and reflection paper serves as a response to a dissertation aimed at exploring inclusion with eight individuals with IDD. The reflection on a qualitative inquiry includes identifying examples of where the traditional research cycle was confronted and adapted in order to engage in research which was accessible and inclusive. Each step in the research cycle (question, design, data collection, data analysis, and dissemination) is shared. Additionally, this response identifies situations where researcher-participant relationship and power dynamics were challenged within the study design and implementation, and how researcher positionality and power may have impacted participation or contribution to knowledge-making processes.

Keywords: self-study, critical inquiry, inclusion, ableism, intellectual and developmental disability (IDD), power dynamics

Individuals with intellectual and developmental disabilities (IDD, significant limitations in intellectual functioning and adaptive behavior originating before age 22; AAIDD, 2021) have traditionally been exploited by and excluded from disability-related research (McDonald et al., 2012; Strnadová & Walmsley, 2017). Not only have they been the victims of grotesque discrimination throughout history (Turnbull & Turnbull, 2000), they have been systematically excluded from research opportunities to bring change or help create a better life (McDonald et al., 2012; Nind & Vinha, 2014; Taylor, 2018). Marked by exploitation, experimentation, and destructive practices, the dark history of research of individuals with IDD exposed the need for significant changes in the ethical considerations of researching human subjects, but also likely contributed to decreased access to research participation for this population (Aman & Handen, 2006; Atkins, 2016; Juritzen et al., 2011; McDonald et al., 2012; Ming et al., 2021). The label of intellectual disability itself undermines an individual's value as an epistemic agent in producing social meanings or knowledge, as it presupposes a diminished level of cognitive ability, followed by assumptions of a diminished ability to share opinions or experiences (Linton, 1998; Taylor, 2018). This results in individuals with IDD being denied the liberty to speak for themselves on issues about their lives, and live in silence (Fyson & Cromby, 2013; Linton, 1998).

Though now considered human beings with rights, individuals with IDD are still regarded as too deficient to understand the world around them and are therefore excluded from opportunities to share or create knowledge (de Haas et al., 2022; Taylor, 2018). Moreover, current research practices systematically prevent many individuals with IDD

from participation (e.g., inaccessible literacy levels and lack of read aloud accommodation; Aldrige, 2007; Elsen et al., 2018). Between the efforts to prevent mistreatment of and to protect marginalized populations (McDonald et al., 2016), the socially accepted view that individuals with IDD will not understand the research or construct knowledge (McDonald et al., 2012; Taylor, 2018), and a distrust of the data or input provided by individuals with IDD, research including individuals with IDD is lacking. Together, these barriers contribute to the epistemicide or killing of knowledge (de Sousa Santos, 2014) from, for, and about disability communities. Not only has research been dirty and painful, but it has led to the silencing and killing of knowledge production.

de Sousa Santos writes that an intellectual abyss exists (2007), and inside that abyss is the knowledge of the disabled. Outside of the abyss is research/academia; the able-bodied person who does not identify as having a disability is in power, therefore responsible for knowledge production, collection, and dissemination. Fals Borda refers to this as a monopoly on experience (Fals Borda & Rahman, 1991) and those in power decide what experiences are valid and taken as truth. This perpetuates systemic exclusion in research and the gap between individuals with IDD and knowledge production. This epistemicide is *particularly* dangerous given that special education and disability research tend to emerge from the social science or social justice fields, and what may be seen as benevolence in fact contributes to injustice (Fine, 2018). While the socio-academic movements have accepted that the lives of individuals with IDD are equal and important, this has not necessarily extended to research; lives are equal but not enough to contribute

to meaning-making, or have knowledge count, or inform change, or certainly not without “help” of a parent or guardian. Individuals with IDD continue to be oppressed through this epistemic injustice (Fine & Torre, 2021).

Further complicating and preventing research with individuals with IDD are legal protections from institutional review boards (IRBs). IRBs are committees within organizations and universities designated to review research proposals involving humans or biomedical research (Kennedy, 2005). Vulnerable populations are given special consideration within IRBs, as they require greater protection than normal against the potential risks of participating in research. This is an obvious necessary protection given the history of research on and about individuals with IDD and these protections are not being disputed; however, it is important to distinguish between compliance (e.g., checkboxes on an IRB document) and researcher ethics (e.g., remaining committed to the participant needs, exercising an ethic of humility; Limes-Taylor Henderson & Esposito, 2019). In order to receive IRB protections, the researcher needs to essentially commit to do “no harm” with little commitment to “do good.” The additional IRB protections are simply compliance steps (e.g., ensuring consent practices are fair and understood by potential participants, ongoing assessment of fitness to participate, and providing opportunity to stop participation). With these accounted for, the research is protected, but this does not necessarily reflect best practices, or remain true to participant needs as such protections were developed by the powerful majority of researchers (e.g., financially stable, temporarily able-bodied, White, male) who are responsible for creating research

and therefore have been able to define who benefits from, who participates in, and who is exploited by research.

Much disability research seeks to understand and fix a problem, with explicit focus on interventions and outcomes, instead of participants or community members. Oftentimes the participants themselves are framed as the problem needing fixing, their disability is the issue, and the researcher has the tools to fix. The little qualitative research that exists and “includes” young adults with IDD often relies on proxies or various stakeholders for data collection (Francis et al., 2014; Taylor, 2018), not the individual with a disability, *or* follows a systematic extractive approach, leaving out the participant. Though there are various methodologies and paradigms which challenge Western ways of knowing by including and centering those with experience as valued experts (e.g., DisCrit, Indigenous methodologies, decolonizing methodologies), there are limited documented approaches specifically dedicated to researchers without known or identified disabilities working with the population of individuals with IDD (Kim et al., 2022; Walmsley et al., 2018). Further, adapting many of these paradigms not only threatens to usurp the foundation on which they were built (e.g., taking over a feminist methodology to claim it as disability-focused, inaccurately representing participatory action research) but they do not necessarily meet the IDD population needs (e.g., work focused solely on community or political change, incorporating frameworks assuming knowledge of analysis procedures) and so working under the umbrella of one of these paradigms may not end or slow the epistemicide for individuals with IDD. Therefore, I posit this work (my dissertation) is primarily rooted in epistemology, and not a methodology at all.

Research Study Background

My dissertation research explored inclusion alongside eight individuals with IDD and centered around perspectives of inclusion as well as recommendations for increasing inclusive experiences at postsecondary education programs (PSEs). The study followed qualitative inquiry design influenced by participatory, narrative, and phenomenological approaches. Purposeful recruitment and selection steps were taken to investigate inclusion from the perspective of individuals with IDD who recently participated in PSEs. The research group, self-named Everyday Friends Research (EFR), met over the course of seven months through Zoom due to COVID-19. Individual interviews, group interviews, and weekly meetings served as primary data collection. Additionally, participants were invited to share visual representations of data and lead meeting conversations related to their own research interests. Stories and experiences shared during our conversations were reviewed and analyzed as a group to develop key themes and deeper meanings behind the stories.

A Response to a Participatory Inquiry Dissertation

In preparation and implementation of the study, I was conflicted with the ethical and moral responsibilities associated with carrying out research which: (a) demonstrated my ability to design and implement research as a primary investigator (satisfying doctorate program guidelines), and (b) attempted to shift the definition or recognition of what constitutes “good” research. Through self-critique and discovery processes during my dissertation I recognized my role in preserving ableism and oppression (people like me staying in power and sharing findings, and people with IDD waiting to be asked for

input with no power over what gets shared, or with whom). In fact, throughout the dissertation study and work with the EFR group, I became equally—if not more—concerned with how the research was being done and less worried about the findings or arriving at an answer to my research questions.

The remainder of this manuscript provides a response to my dissertation in which I reflect on methodological choices and the tensions which emerged during the research process. First, I share my positionality and onto-epistemological stances which frame my work. Next, I provide a reflection of my dissertation procedures, including how I attempted to confront the traditional research cycle through this study with individuals with IDD and reflect on the challenges and shortcomings as a result of power dynamics and imbalances, and ableism. I consider situations when trust was broken as outlined by Paulo Freire's trust through dialogue (1970) as a discovery and knowledge production process. Last, I conclude with remaining tensions and future research recommendations.

Positionality and Onto-Epistemological Stances

I approach the world of research with a background in education and instruction, specifically, special education and providing explicit instruction in adapted, segregated settings. As a high school teacher, I was constantly searching for how to get my class involved, pushing boundaries for class placements, and creating curriculum alongside general education peers. However, reflecting back, I can acknowledge now that I was likely championing inclusion based on my own set of beliefs, and not at the request of my students. Through reflections on examples like this, I continue to reexamine my positionality as it relates to teaching, research, and ways of learning and knowing.

I identify as a White, middle-class woman who does not have a disability (currently), and have benefitted from the White patriarchal systems of this county and institutes of higher education (i.e., academia). I benefit as a White woman in the United States, and as a result my epistemology is entangled in privilege and ignorance (hooks, 1984; Mills, 1997). This is important to recognize and explicitly acknowledge because while I strive to engage in research that is equitable, I can not ignore the systems in place that consistently benefit me and exclude others.

The development of this inclusive participatory inquiry design emerged from my onto-epistemological belief that individuals are experts in their lived experiences as well as a desire to engage in work that is equitable, inclusive, and responsive to participants or community members. Further, my critical interpretivist standpoint guided my work and acknowledged that we can only know through socially constructed meanings, and that I am dependent on others to learn and know of an experience. Throughout the design, analysis, and writing of this study I was flooded with discomfort from the tension surrounding what it meant to engage in research with individuals with IDD, especially those to whom I am connected through the Special Olympics and local school district communities. I feel called to this work and am committed to entering the fields of education and disability research alongside people who want to make changes, but no one has asked me for help. I do not identify as a person with a disability so am I wanted? If I believe change is necessary but have not been asked to help or support, is change actually necessary or am I just continuing the imbalance of power which prevents individuals with IDD from making decisions and constructing knowledge? These are among a few

questions I continued returning to throughout the study, as well as reflecting on the following onto-epistemological stances.

I Will Label but Not Other: I Labeled, but did I Other?

Labels and exclusion of marginalized groups are systematic, systemic, and can devalue individuals resulting in the destruction of social justice and epistemological progress (Wolfensberger, 2000). Paradoxically, inclusion of individuals with IDD has only been made possible through such exclusionary measures (Slee, 2019), including the acknowledgement and subsequent labeling of individuals as disabled. The label of IDD itself undermines an individual's value as an epistemic agent in producing social meanings or knowledge. Yet, it is *with* this label that individuals with IDD are separated from current researchers, and *because* of this label the EFR members have expertise in areas I (and the majority of authors) will never have.

Additionally, I struggle with the term “vulnerable population” as a label in research, and one I specifically write about in order to conduct the work. I consistently acknowledge and lean on Limes-Taylor Henderson and Esposito's (2019) ethic of humility question: To whom is my research accountable? With the answer being the EFR team, and future participants (i.e., students, and their families) in an effort to promote inclusion. I wrestle with “vulnerable” as I think this type of language is exactly what keeps the research sphere exclusive and inequitable. By labeling “vulnerable,” we are assuming. This is not to argue against very necessary safeguards for human subjects in research, but rather my stance on naming individuals.

I Consider Experiences as Expertise

The concept of experience as expertise has been well-cited throughout the fields of philosophy and sociology yet remains to be qualified in research involving individuals with IDD (Collins, 2018). Not unlike the label of IDD or vulnerable, expertise is an exclusionary concept. Being an expert in a community automatically creates a boundary between members of a group and the experts (Taylor, 2018) which adds to or generates new situations of injustice in educational research. Specifically, in disability research, the experts (I) have emerged as such because I was given more educational and social opportunities to become an expert (e.g., exposure to general education, higher education, research opportunities). I believe expertise comes with experience—not just formal training. To become an expert in an area of life, one must be embedded in the social life of said area, where tacit knowledge can be acquired (Collins, 2018; Nind et al., 2016). Individuals with IDD who have attended PSEs have personal and tacit knowledge of experiences with inclusive PSE settings, therefore, are experts and can provide explicit knowledge that cannot otherwise be meaningfully understood.

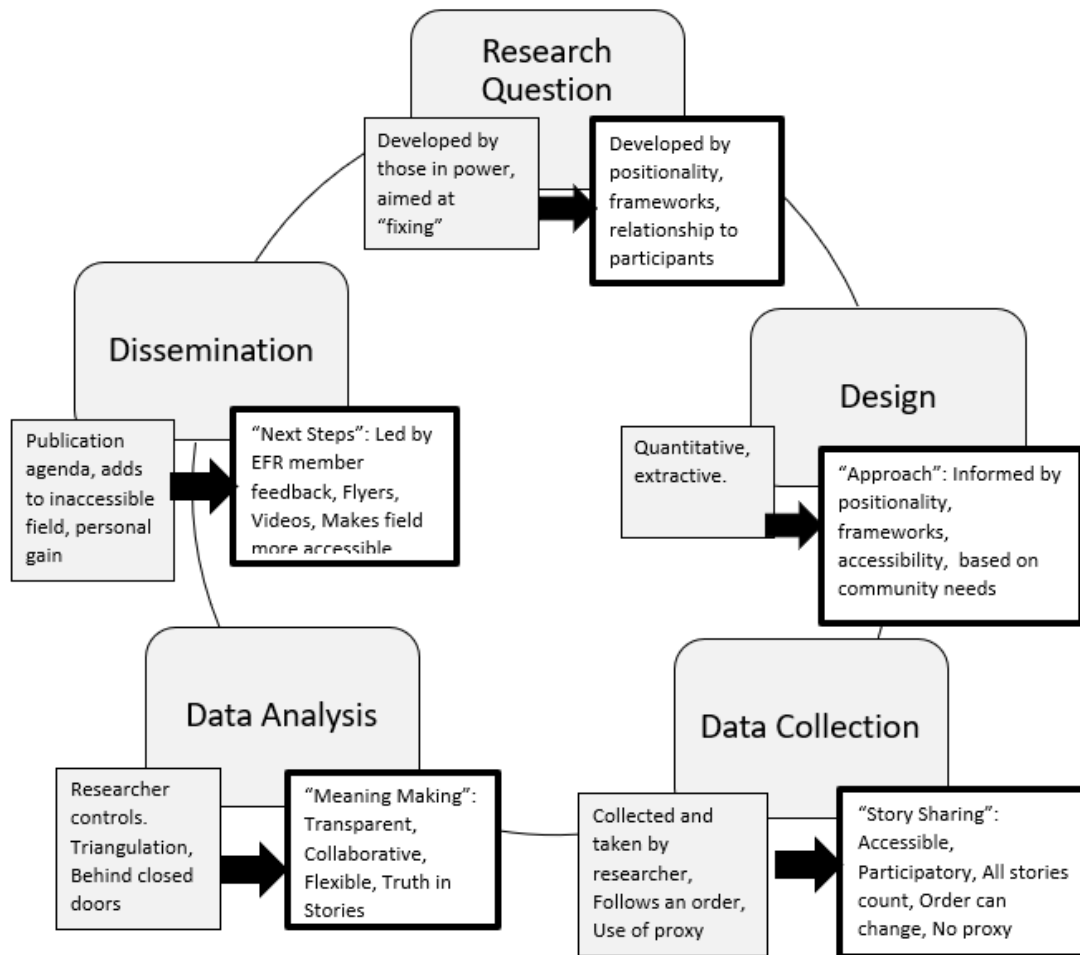
Trust Through Dialogue

Engaging in dialogue, storytelling, and critical conversations is essential to discovery and knowledge production. In particular, I lean on Paulo Freire, Orlando Fals Borda, and those who have built upon their work (Michelle Fine, Maria Torre) in my belief that conversations with those who have been most or traditionally excluded provide the greatest opportunity for new, authentic knowledge production. For too long, knowledge and inquiry has been (and still is) monopolized (Fals Borda & Rahman, 1991)

and efforts must continue to decentralize ownership or production of knowledge by reimagining what knowledge can be (Gaventa, 1991). Freire writes about the trust through dialogue process needed for discovery and understanding reality, and that in order for trust to flourish, love, humility, faith, and hope must also be present (Freire, 1970). That is, in order to understand someone or engage in research which actually includes and creates meaning, I need to engage in open conversations as a communication partner, not an expert or keeper of knowledge. Further, I cannot solely direct or manufacture the dialogue and research process through rigid protocols or a “crafty instrument” (Freire, 1970, p. 68) to answer my research question as that would continue monopolizing the knowledge production process. Ultimately, this onto-epistemological stance is rooted in the importance of conversations, story-sharing, and listening as means to create new or recognize knowledge.

Confronting the Traditional Research Cycle

The traditional research cycle involves a five-step process which typically excludes the individual with IDD at each stage: (a) develop a research question, (b) design a study, (c) engage in data collection, (d) perform data analysis, and (e) disseminate findings. In an effort to disrupt tradition and shift whose knowledge and research counts (Fine & Torre, 2021), I confronted this research cycle as I developed this dissertation study (see Figure 1). What follows are reflections from the work.



Note. This figure demonstrates the five basic steps of the research cycle of a typical research study done “on” or “about” individuals with IDD (gray) and outlines my intention for participatory and collaborative inquiry at each stage during the dissertation (white). Adapted from “Considerations for Engaging in Research with Individuals with Disabilities” by A. S. Reed & G. L. Francis, 2021, in C. C Reyes, S. J. Haines, & K. Clark-Keefe (Eds.), *Humanizing Methodology: Culturally Appreciative Methods for Working With Vulnerable Populations in Qualitative Research* (pp. 110-117). Teachers College Press.

Figure 1

Traditional Research Cycle Confronted

Confronting Step 1: Research Questions

Traditionally, research questions are developed by those in power with a desire to investigate, make a change, or fix something. The very act of developing a research question (for a dissertation, publication, or otherwise) in order to help others assumes that I have a power and influence someone else does not have. Further, it assumes there is a problem or something in need of reexamination or change. As a White woman, currently nondisabled, with a lifetime benefitting from educational structures now working within special education and higher education, it was important and necessary to frame my research question(s) in ways that took the power from those systems and gave to the community I am interested in working alongside. I did not want to investigate how I (the powers that be) can help or change for Them, and wherever possible wanted to avoid, or call out as needed, the saviorism so rooted in this ableist society. My shift in research ponderings from “how to improve higher education” to “what are the experts saying” resulted in research questions focused on perspectives of individuals with IDD on inclusion and recommendations from individuals with IDD. In a demonstration of humility and faith, I conceded my knowledge of “inclusion” as it was in my former public school classroom, and trusted that the individuals I would soon be working with would inform and change my understanding through their stories. In confronting the traditional cycle I acknowledged my position of power to be able to ask the question and eventually lead a study, with the hope that I used that power to shift the question from me (i.e., higher education programs) saving others, to creating the space for the experts to construct and share knowledge. In fact, from the beginning of my research path (i.e.,

literature review) my interest shifted from wanting to understand inclusion from the perspectives of individuals with IDD to simply wanting to engage in meaning-making, to reimagine what research can be, and who it can represent.

Confronting Step 2: Approach

Though described as qualitative “design,” my approach to this study was rooted more in epistemology over methodology. It was clear that the traditional extractive approach tied to outcomes, performance, and statistical validity would not support the inquiry. However, existing methodologies and tools within qualitative inquiry did not provide a “best fit” for our research group either. Engaging in work that was accessible, meaningful, and EFR group-directed was more important than implementing a “textbook” methods study. An obvious confrontation to the traditional research cycle step of design was the lack of naming and constructing the study. While participatory focused, this was not PAR; while focused on narratives and stories of inclusion, this was not narrative inquiry; and while initial interest centered on the phenomenon of inclusion, this was not solely phenomenological inquiry. I knew this would be an area of critique or weakness, but also resisted manufacturing a study in order to fit in one of the five main qualitative methodological “buckets” as that perpetuates the very nature of why individuals with IDD are left behind in research.

Through my unique access to networks of individuals with IDD and their families (i.e., county special education, local Special Olympics, existing relationships with postsecondary education program alumni and staff) I was able to recruit and select purposefully within the community (Patton, 2015; Reybold et al., 2013). I had prior

personal relationships with all EFR members in varying roles (e.g., teacher, coach) for varying lengths of time ranging from three to nine years. This could be seen as a conflict of interest in traditional research, but was an asset (I hoped) in our work. This could have been a catalyst for the eventual power imbalances and tension, but was a methodological decision made because of (my) perceived positive relationships with community members. First, I did not want family or parental influence (e.g., guardians signing up their young adult and providing the consent so “it would be okay”), and second, developing, earning, or maintaining the trust and safety was more important to me than a perfect heterogenized sample.

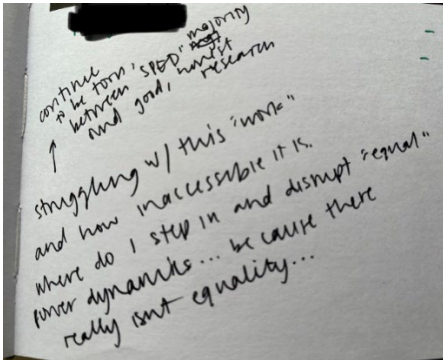
Eight individuals participated in the study as members of our research group which quickly became named the Everyday Friends Research group (EFR). None of the eight EFR members had participated in research before, and in an attempt to confront traditional research, I modeled a participatory approach assuming (requiring) that all participants are actively involved in guiding the study, engaging in conversation, constructing analyses. While my intention was to engage in discussions without explicit roles or hierarchy, it became quickly clear that what sounded fair and right (e.g., we are all equal, we are all researchers) was not what truly was fair and right, or preferred by the group members. I could see the glazed-over eyes or fleeting looks of panic in EFR member faces when I excitedly told them “you are the experts, we are co-researchers!”

The terms co-researcher and team member were used instead of participant as part of a decision to authentically include individuals in the process. The power of language and naming has long been documented in disability studies (Morgan et al., 2014; Parsloe,

2015), and it was my intention to use language explicitly to confront the research cycle and shift the understanding of what this population can and should be doing—constructing knowledge and making changes to lives. With this, however, came the tension of assigning a new label—co-researcher—to those who did not explicitly sign up to be named a researcher. Misguidedly, I had placed stress and responsibility on this group I cared deeply about with an expectation to participate as a researcher and as a result had to shift my focus and reframe what participation looks like. This reframing was especially necessary given the EFR group was recruited, formed, and managed by me. This was not a participatory or action research study, this was an inquiry with a goal of inclusive design which should have recognized all levels or forms of participation and motivation to engage with the work.

While I had hoped my “flexible participatory design” would lead to the emergence of co-researchers and leaders, what I observed was a group of people perfectly fine participating as members and following my lead. Additionally, my label and assertion of EFR members as experts on inclusion assumed a level of interest, background knowledge, and buy-in. This was especially made clear during our initial discussions about inclusion as the research topic with a few of the team members and exemplified by a research journal memo in Figure 2. I remember feeling so gutted when, after meeting two times (once individually to outline the study and goals and once as a group in our initial community building session), Yahya asked me “what is inclusion?” Teddy also shrugged and mentioned he “hadn’t heard about it [inclusion] in a while.” I

worried if this work mattered or could turn into “something,” especially if the only one talking or thinking about inclusion was me!



Note. “Struggling with this ‘work’ and how inaccessible it is. Where do I step in and disrupt ‘equal’ power dynamics because there really isn’t equality...continue to be torn between SPED majority and good, honest research.”

Figure 2

Researcher Memo

Another example of the need to reexamine or reflect on my goal of “equity” in research is my long pause and (awkward) chuckle in response to Lara simply asking “why” when I told her she was the expert. I had been so focused on working against “big systems” power dynamics and toward justice and equity that I was missing the requests from the community. This expectation, I believe, resulted in some trust broken by my lack of humility (assuming I knew the best way for EFR members to “do research”) and faith (not considering the existing contributions as enough).

Relatedly, allowing participation to take place naturally/at the pace and choosing EFR members helped to foster a research space that was safe (hopefully) and welcoming,

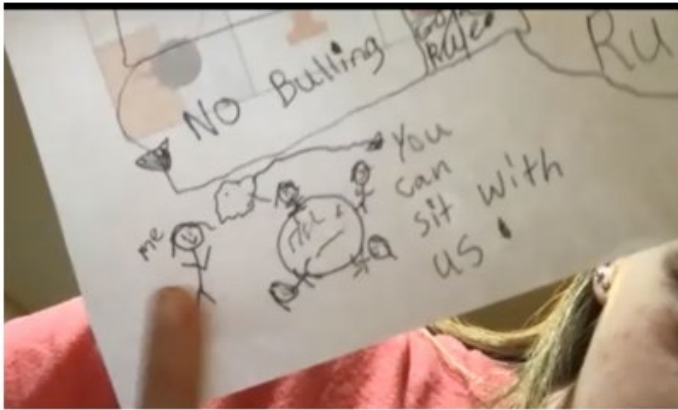
and not based on performance or completion/quality of input. Out of the eight team members, four emerged as the primary “speakers” (Yahya, Teddy, Veronica, Ann, e.g., responding quite immediately after I posed a question or asked for opinions); Mary and Rikki were primary chatbox users and emailers; Sophia primarily listened and nodded, providing short commentary or facial expressions; and Lara participated primarily through observing—all participating! To intervene and limit a primary speaker or call out a primary listener to speak up more may have caused harm, disrupted, and/or contributed to epistemic injustice within our group. Trusting the EFR members to guide their own participation facilitated greater dialogue and meaning-making, and is likely why Mary and I are still in touch today, months after our official last meeting!

Confronting Step 3: Data Collection

Much of the research including students with IDD asks how they felt about the inclusion. Approaching this way forces choice and takes advantage of possible power and acquiescence—you were included, we said so, tell us about it so we can add it to the literature. I wanted data collection to be a shared responsibility among myself and the EFR team, confronting the traditional cycle of “researcher designs and then takes.” However, as noted in my story of equal participation above, I quickly realized it might be necessary for me to take on some of the “traditional” data collection responsibility, knowing that engaging in research was a new activity and process for EFR members. As a term, “data collection” was not used throughout the study and instead we had conversations (individual interviews and group meetings), shared stories and memories, drew pictures, shared photographs, and wrote individual questions and goals—all of

which make up “data.” This was another attempted confrontation: to make explicit and transparent all of our research activities.

Throughout our conversations, interviews, and group meetings it was critical for me (internally and out loud in front of the research group) to acknowledge all forms of participation and data shared as valuable and important to our work. Not only did these different data sources add to the study findings, but they disrupt traditional research and influence “what” and “who” counts. It was important for our community to welcome all EFR member input as they were valued storytellers and co-creators of knowledge, as seen in Figure 3.



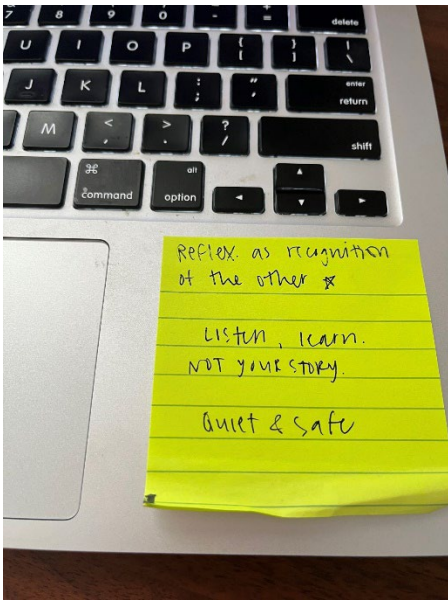
Note. Top: A drawing from Rikki representing inclusion. Friends are sitting at a table inviting her to join them for lunch with the caption “You can sit with us.” “No Bullying” and “Golden Rule” are captioned as well. Bottom: A photograph from Veronica representing inclusion: “We were having some kind of a hangout together, I believe, having a drink, like usual, and we were hanging out. That was a day of my sister, [Name], and my brother-in-law [Name’s] anniversary.”

Figure 3

Visual Data Examples

It was during the “data collection” phase that I struggled—embarrassingly so—with my own positionality and ableism, especially as I attempted to confront the

traditional research cycle. As I have shared, I approached this work with a background in special education and teaching with unique access to and knowledge of the EFR members through varying relationship dynamics (teacher–student, coach–athlete, advocacy organization member–advocate). With this unique position came a substantial amount of background knowledge and preconceived beliefs, and it became a consistent internal battle between listening and learning in a space of trusting dialogue, and interrupting or contradicting as the researcher “in power.” For example, when someone would mention Best Buddies (an organization designed for individuals with disabilities) as inclusive, my notes and margins were filled with “?” and “ugh, 😞” indicating my knee-jerk reactions and personal disagreement with the story or jumping ahead with assumptions and analysis. Yet, these were not my stories, I was the outsider, and no amount of special education teaching or education research methods coursework or texts would change this. As a (temporarily) able-bodied White middle class woman who did not (temporarily) identify as having an intellectual disability, I was listening and reacting without experience, potentially contributing to the silencing of the EFR members. Memoing and engaging in reflexive practices (see Figure 4) helped to call myself out and limit these interruptions, but they still existed, and exist.



Note. This reminder, adapted from Pillow (2003) served as reminder for reciprocity with EFR members and the importance of validity claims and knowing the other: “Reflexivity as recognition of the other,” a reminder of my outsider status with EFR, and these were not my stories. Adapted from “Confession, Catharsis, or Cure? Rethinking the Uses of Reflexivity as a Methodological Power in Qualitative Research” by W. Pillow, *International Journal of Qualitative Studies in Education*, 16(2), 175–196, <https://doi.org/10.1080/0951839032000060635>.

Figure 4

Research Memo as a Reminder

Typically our conversations followed the protocol and more notably the protocol rhythm of “I ask, I wait, they answer, they wait for the next question.” This was often uncomfortable as it felt extremely researcher–subject—how could this be confronting tradition? But generally the EFR group preferred this. I was trusted and (it seemed) they depended on me to set the tone or direction of our conversations. Throughout the researcher journal I jotted “be okay with the waiting,” “uncomfy is ok,” and “trust them,” often in direct reaction to/in-the-moment call-outs of my own ableism. Assuming the

other individuals on our team needed to direct a conversation “or else it doesn’t count” ignores the participation and knowledge production that *was* taking place.

Alternatively, when EFR members did choose to direct a conversation, I also felt conflict between excitement and pride for our work and worry about the rigor of content and how it would be perceived by non-EFR members (i.e., academia). One notable example of this tension took place when an EFR member led a group meeting. All EFR team members were invited to develop their own meeting topics and questions to pose to the group. This was not required, and was presented to the group as a chance to change my research, or focus on something they were specifically interested in. With that, some members developed a list of questions (similar to my protocols) surrounding inclusion, being bullied, favorite college memories, and employment. Other members asked questions unrelated to the study. Yahya’s meeting questions were at first glance completely “off topic,” but as the group discussion went on, I noted some of the “best” conversations we had had so far, seen in Figure 5.

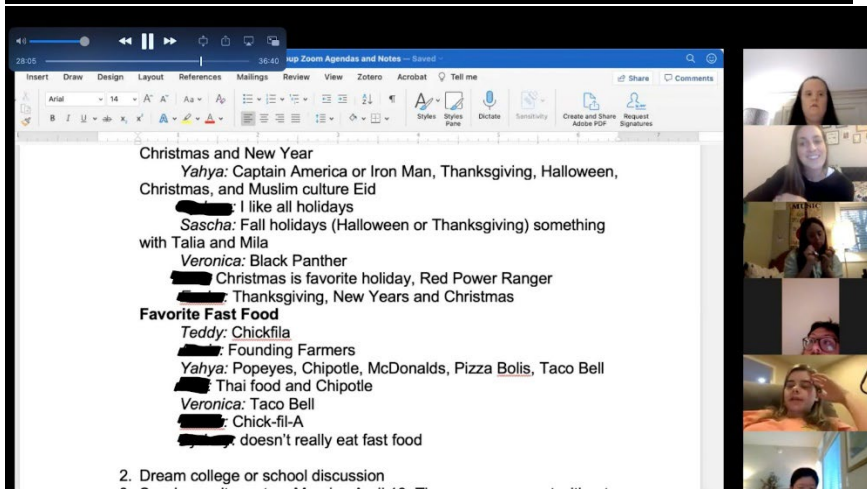
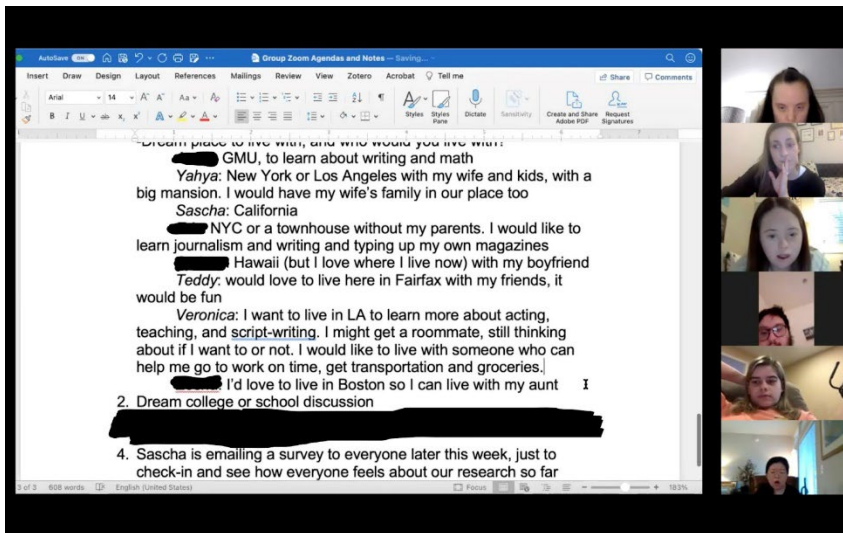
1. [REDACTED] Leads!
- How do you feel when you go outside/go for a walk and out of nowhere the rain comes down and you have no sweater or jacket, and your headphones are on?
 - Favorite movie or favorite TV show
 - [REDACTED]: Diners Drive-Ins and Dives
 - [REDACTED]: Musical movies, Star Wars movies, FreeForm TV channel
 - Dream place to live with, and who would you live with?
 - [REDACTED]: GMU, to learn about writing and math
 - [REDACTED]: New York or Los Angeles with my wife and kids, with a big mansion. I would have my wife's family in our place too
 - [REDACTED]: California
 - [REDACTED]: NYC or a townhouse without my parents bothering me. I would like to learn journalism and writing and typing up my own magazines
 - [REDACTED]: Hawaii (but I love where I live now) with my boyfriend
 - [REDACTED]: would love to live here in Fairfax with my friends, it would be fun
 - [REDACTED]: I want to live in LA to learn more about acting, teaching, and script-writing. I might get a roommate, still thinking about if I want to or not. I would like to live with someone who can help me go to work on time, get transportation and groceries.
 - [REDACTED]: I'd love to live in Boston so I can live with my aunt

Note. This is a screenshot of Yahya's questions. Each bulletpoint was a question he posed to the group and individual member answers are listed below. During this meeting I wrote answers verbatim as part of our running-notes and agenda process.

Figure 5

Everyday Friends Research Group (EFR) Member Leading Group Discussion

This discussion included topics ranging from fast food to future living dreams, and the power of discussion and community was really evident in EFR group responses and laughter (Figure 6).



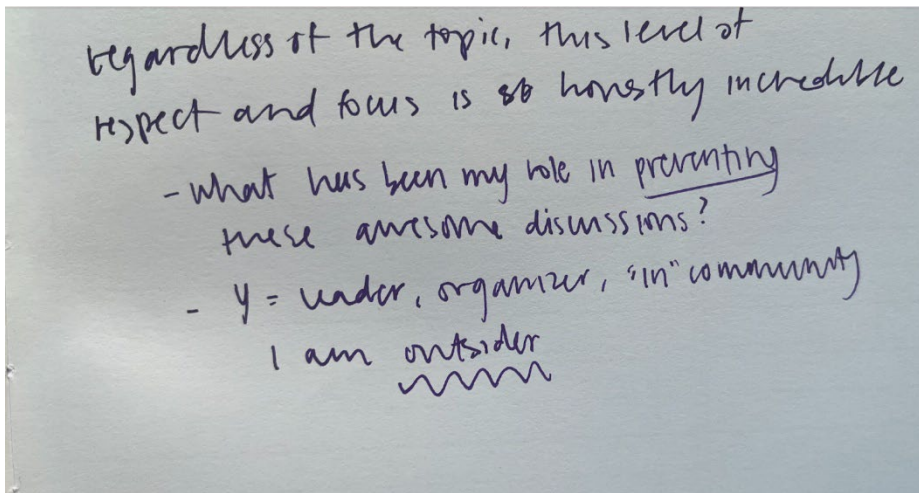
Note. Screen capture images from a discussion led by Yahya. Each bulletpoint was a question he posed to the group and individual member answers are listed below. During this meeting I wrote answers verbatim as part of our running-notes and agenda process.

Figure 6

Screenshot of Group Zoom Discussion

In fact, as a result of this discussion I adapted one of my group protocols to include questions about our dream college and dream place to live. Lara and Rikki participated (verbally, enthusiastically) more during his lead than any other meeting. This discussion

exemplified what can be wrong with the research cycle and how traditional data collection can be a barrier. Trusting through dialogue requires love and faith: Love for one another and valuing EFR members as well as faith in their participation, abilities, and production of knowledge. Our group was sharing their opinions and experiences and their truths led to more meaning-making! Figure 7 is a portion of memoing from this day.



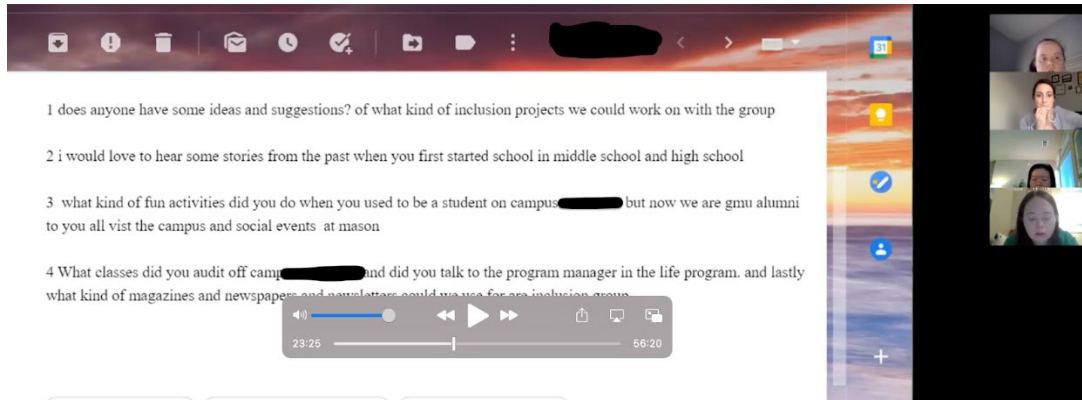
Note. Researcher memo during an EFR team member leading meeting. “Regardless of the topic, this level of respect and focus is honestly incredible...what has been my role in preventing these awesome discussions? Y = a leader, organizer, ‘in’ [the] community, I am an outsider.”

Figure 7

Research Memo

Tensions surrounding data collection were rooted in my concern for how this work was perceived (e.g., was this research-y enough) as well as how the research team was perceived (e.g., wanting to protect the EFR members)—both symptoms of systemic ableism and epistemic injustice (Catala, 2020; Woodfield & Freedman, 2021). In order to

hold fast to the conviction of knowledge production through dialogue, I needed to reimagine what data was, and could be. Figure 8 is an example of another EFR-led meeting and the protocol created by Mary.



Note. Figure 8 displays a screen capture of a Zoom call led by Mary.

Figure 8

Meeting Protocol Developed by EFR Member

Confronting Step 4: Data Analysis as Meaning-Making

Confronting the traditional data analysis procedures (e.g., studying Others by gathering their data and analyzing separately; Fine & Torre, 2021) by making explicit decisions surrounding our team procedures was important. Breaking down the purpose of analysis through familiar language and modeling my process for EFR members created a transparent process. This helped make analysis accessible (e.g., eliminated research jargon, plain summaries, in vivo coding) but did not prevent tension. Traditional analysis requires independent coding, triangulation, checks on reliability and validity. Outsourcing

this analysis to another researcher or triangulating stories with proxy input (e.g., EFR family members or guardians) may have satisfied traditional critiques of analysis, but yet again presupposes EFR members' inability to generate meaning. Conversely assigning team members independent coding of our data (i.e., transcripts, video recordings, images, emails) in the spirit of objectivity and inter-rater reliability would have been an unexpected or unfamiliar task (or, honestly, burden) for team members. With these considerations and my commitment to expertise and trusting through dialogue, our team engaged in group analysis and I (hopefully) lovingly modeled and guided this process to support all levels of participation. As our meetings began, I was initially independently memoing and developing codes, without the explicit knowledge of EFR members. I would add "ooh that's cool I'm writing that down," but did not explicitly label this as an analysis step. This felt sneaky, however, and the eventual reconciliation came from a teaching lens; how can I expect someone to do something (analyze) they have never been exposed to or taught? So, in another attempt to confront traditional analysis I turned analysis into a transparent process. During conversations I would pause and share "I just heard ___, and this is the third time I've heard it. That makes me think ___ is important. This might be something our group should share with other people like students, professors, or teachers." With clear examples and plain language, I was attempting to teach and turn over the tools for analysis to the team, in order to democratize this process. Figure 9 shows an example of analysis discussion, in which pieces of data were displayed on screen, and EFR members shared the meaning behind the story in their own words.

FRIENDS THAT “GET ME”

| | | |
|--|--|---|
| No, it didn't matter to me because I love it. Because, I told my sisters and my brothers that I see the down syndrome or any people that have disabilities, I see them as my buddies, as my friends | People with disabilities are my friends | I feel like I belong when I'm with others with disabilities |
| I remember that. I was making friends that have a disability, which actually amazed me because I never thought that I was making new friends since I moved to Virginia for the first time | I liked having friends with a disability | It is important to have friends with disability |
| I remember the JC cinema. Oh my gosh, some were amazing. I've got friends who work at the cinema anyway. I always visit them always. I had a picture with them anyway in Facebook. And then, I had so much fun. I remember went to so many movies with Max, Stephanie, Christian and PK. I remember we went to see Rio movie when it came out and we watch it in JC cinema. It was so much fun | | I like to do activities with my friends on our own |
| | | Doing things together with friends like me is important and inclusion |

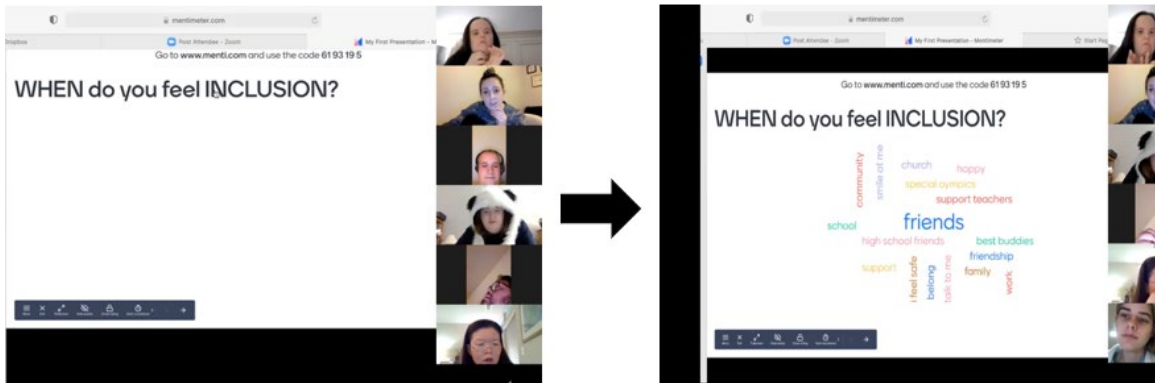
Note. A screen capture of pieces of data shared followed by Everyday Friends Research Group (EFR) meaning-making and summarizing as a step in analysis.

Figure 9

Example of Analysis Discussion

Similar to my conflicts during data collection, I caught myself correcting or judging the language and stories shared. My unique access (e.g., knowing a member's family or living situation) often resulted in breaking trust as I questioned who outside of our group would “believe” or take the story seriously, much less understand it as a truth. This was a tension felt particularly when discussing inclusion as it related to disability-centric spaces (e.g., Special Olympics, Best Buddies, segregated classes) as I often needed to “check my privilege and ableism” at the proverbial door/Zoom waiting room door and monitor my language and reaction in responses and member checking. Questioning how an experience could be inclusive based on my perspective of an organization prevents the knowledge production of young adults with IDD through

shared experiences. Basically, “who am I to question?” This also led to my navigating potential acquiescence and where or what my role was in preventing it. Does my assumption they are acquiescing to me perpetuate a power struggle? Am I using my power responsibly, or could I have provided more guidance and space to answer differently if they needed? The delicate walk between ableism and acquiescence continues to haunt this work and likely future work. Perhaps, the best reflection offered or lesson learned is to follow the least dangerous assumption: presume competence, and have faith in our relationships, the member-checking process, and listening to the words (Figure 10).

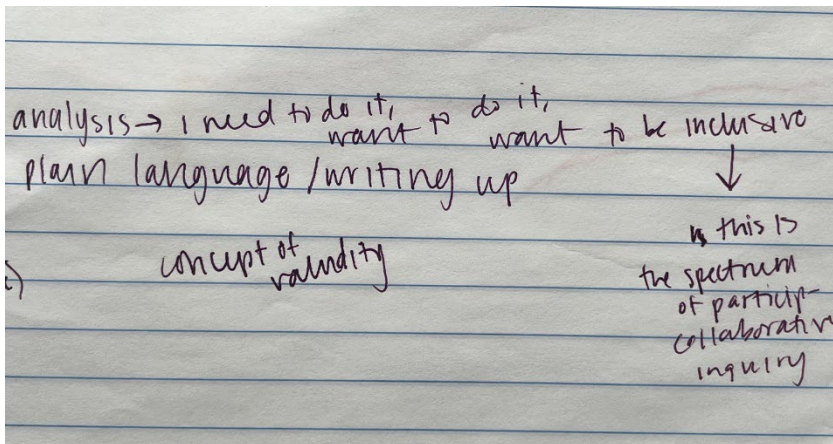


Note. The Everyday Friends Research Group (EFR) generated a visual representation of “inclusion” through sharing important words or phrases.

Figure 10

Word Cloud Representing Inclusion

Lastly, in confronting the traditional research cycle I wanted analysis to be participatory, for all to “enjoy!” However, I was met with the tension of participation; when does it stop being voluntary? Did someone’s participation and “equity” (e.g., “I need them to analyze so it can be participatory,” see Figure 11) mean more than their autonomy? Reframing participation to include all forms (as well as the choice *not* to participate) may have impacted my “findings” but disrupted the cycle of researcher–participant power which has far greater implications than supporting or adding to a theme.

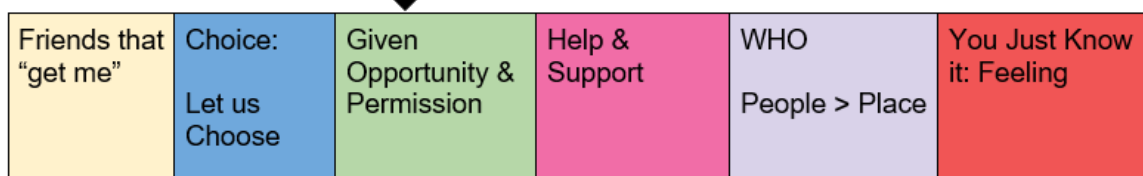
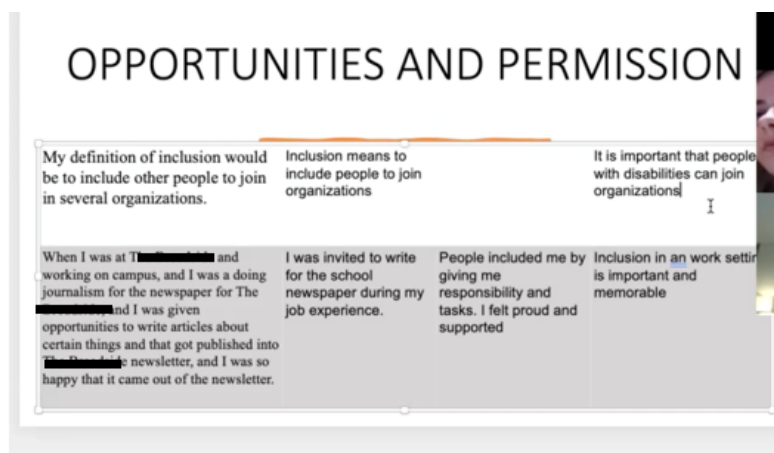


Note. Researcher memo: “Analysis: I need to do it, want to do it, want to be inclusive...this is the spectrum of participatory/collaborative inquiry.”

Figure 11

Researcher Memo Related to Analysis

The goal of this research was to engage in conversations as a group and create or allow a space for meaningful authentic participation in research. The term “findings” stirs mixed emotions because as a researcher I listened and humbly joined a community as the outsider. “Findings” elicits discovery and implies the reliance on power structures; I researched, discovered, and took, now I can share my findings. Even in my theming and naming (see Figure 12), “let” us choose, “given” permission is reinforcing that this population is powerless. My language is saying they should be powerless until we/staff/majority gives them the right. Is this an example of trust broken? Either way is lacking faith in EFR and our work, or lacking hope that the work will be received regardless of the language we use.



Note. Summary of a group analysis discussion and how it formed the key theme of “inclusion is being given opportunity and permission.”

Figure 12

Stories Shared Leading to Development of Theme of Inclusion

Confronting Step 5: Next Steps

The next steps and dissemination in a traditional research cycle typically follow the findings, and inform new decisions or policies. This is where I am now, disappointed in that my first actionable “next step” is not informed by EFR members, but instead by the findings and my publication goals. While this was not a critical participatory action research (CPAR) study, in the spirit of participatory inquiry and inclusion the first EFR “product” really should have been something co-constructed to give back to the EFR

group or IDD community (Fine & Torre, 2021). Instead, I share this dissertation as a single author. I was transparent with the research study direction and purpose, describing a dissertation and who my future audience would likely be (e.g., professionals, faculty). EFR members, however, were not interested in this audience and instead were excited to create media for students with IDD and families considering college in the future! Authentic confrontation or disruption of the research cycle at this stage should be creating our YouTube and SnapChat video as a research collective. This remains an agenda item for our group. I take this time to acknowledge the challenge surrounding publication versus sharing findings in an accessible way.

Further, in preparation for manuscript submission and sharing findings, I struggled to have faith in or show love for EFR team members as co-authors and co-creators of this work, an additional break in trust. Sharing (publishing) these stories is important—critical, in fact—to democratizing the knowledge production process and shifting the belief of who contributes to knowledge. In order to protect or de-identify participants in research, pseudonyms are often used. I explained this to all EFR group members during individual conversations, with the expectation that all would choose or select a new name. Quizzically, Teddy looked at me in response and simply said “why can’t I have my name?” Almost immediately I wanted to respond with “to protect you!” but paused, and took the opportunity for reflection. For as long as research has been published, individuals with IDD have been excluded from constructing new knowledge explicitly (i.e., ignored, not asked to participate) and implicitly (i.e., use of proxies or researcher voice shares findings). This work sought to confront traditional research, and

disrupt the traditional voice and authors in research. Why, then, was I so consumed with applying pseudonyms to members of the research group? Does naming or forcing to choose a new name take away from someone's story? Was this ableism? Savorism? Was I acting benevolently "to protect" or, in fact, selfishly to preserve the inaccessible systems which uphold research? In commitment to EFR members, I used the names each person requested, I still struggle with this, and will continue to after possible publication.

Additional Tensions and Future Research

Throughout the planning and implementation of this study, I returned to the inner dialogue that I was straddling two separate fields (special education or disability research and qualitative inquiry). And now I find myself torn between proving I can execute research and doing work that is accessible and meaningful. Education research is heavily linked to outcomes, scores, and progress. Meaningful research *may* also be linked to these, but there is no way to understand what is meaningful or valued without returning directly to the participant or community members. It is evident that ideologically and epistemologically I was positioned to undertake a disability studies and methods-focused dissertation, yet I was committed to and still plan to work in the field of special education as it is important to me to be connected to that field of research as well as teacher education for teachers or service providers of individuals identified as IDD. Because of these two separated, yet connected fields, it was important to me to investigate not only the concepts of inclusion for the field of special education, but also to investigate *how* I approached this investigation, for the field of research methodology and design with participants with disabilities.

The historic experimentation on and exclusion of individuals with IDD in research has resulted in a field of special education or disability-focused studies which lacks these expert voices and perspectives (Strnadová & Walmsley, 2017). Arundhati Roy (2004) famously wrote: “There’s really no such thing as the ‘voiceless.’ There are only the deliberately silenced, or the preferably unheard.” Significant amounts of research have been dedicated to “fixing” individuals with disabilities through intervention, evidence-based practices, and UDL considerations to help individuals “catch up” or “blend in” with society and schools. This research helped close gaps in academic progress, but the voice of students and individuals with IDD remains (preferably) unheard. As practioners and researchers, I propose we take the good from this research (e.g., strategies to support understanding, best practices to increase accessibility) and incorporate it into increasing participation in research. Further, we need to be aiming to increase participation which is meaningful and valuable to the individual—through deliberately listenining and centering these voices.

Excited and inspired by calls to action for experimenting with methodologies and representation (Denzin, 2017), I had hoped to, in an attempt to disrupt, at least confront tradition and open up how future research can be executed or valued. Questions remain, however. Did I approach this community because they are low-hanging fruit? Did I proceed with humility? Intentionality? As a qualitative researcher, did I proceed ethically or cause more damage by seeking out an individual and inaccurately naming him or her an “expert” and opening up memories or dialogue that was not meaningful, unnecessary, or even painful? As a research expert did I accomplish developing a study successfully?

Over the seven months in meetings with the EFR group, it became more about our group—spending time together and discussing what we wanted to accomplish—than my dissertation, yet I still move forward at this point with a personal goal of publication.

Conclusion

Confronting the research cycle for this work has meant confronting my work and intention, and questioning the value that I add versus the damage I have caused or preservation of the status quo. This an uncomfortable but important position, especially as I wrestle with acknowledging and naming limitations (study size, length, analysis procedures) to satisfy powers, while not agreeing that those limitations are in fact weaknesses but methodological or epistemological choices. Conversely, I wrestle with other choices in my pursuit of confronting tradition and question my power and ableism as the primary limitations.

Frankly, none of these reflections on the dissertation should be considered innovative or revolutionary because this reflexive practice needs to become the norm in the pursuit of good, equitable research. Further, the work can not be accepted as a “warm and fuzzy” study conducted with rose-colored glasses “in the spirit of including.” A refrain often heard and rewarded in academia, “how great of me to include them” only perpetuates the ableism in research and epistemic injustice in society. Rather, this work attempts to—and should—stand on its own as research. Through this work meaning and knowledge have been constructed, and a new or more current understanding of inclusion exists because of our learning with/along and from the EFR group, not simply because I invited them to my table.

As a whole, this work is not revolutionary (or should not be considered as such) but it is a wake-up call and call for a change to institutes of higher education and special education research communities to practice what they preach. Countless professional development courses, seminars, and community learning groups have been dedicated to diversity equity and inclusion initiatives, increasing access for all through UDL guidelines, and resetting high expectations across research communities and institutions. These should be considered as a first step. To truly confront tradition (research cycle or entire paradigms), an adjustment of the concept of research and publication is necessary. Alternatively put, work which includes all people should not be new! Using inclusive practices and trusting through conversation should not be shaking the research foundation, yet it is because of the historic systems dedicated to keeping the majority in power through labels and ableism.

I write this bluntly, but acknowledge I am part of the problem. It is hopefully through these brief confrontations and thoughtful reflections that small acts of sabotage can start and continue to transform academia and celebrate all ways of knowing.

References for Third Manuscript

- Aldrige, J. (2007). Picture this: The use of participatory photographic research methods with people with learning disabilities. *Disability & Society*, 22(1), 1–17.
<https://doi.org/10.1080/09687590601056006>
- Aman, M., & Handen, B. (2006). Reactions to “Ethical challenges and complexities of including people with intellectual disability as participants in research” by Dr. Teresa Iacono. *Journal of Intellectual & Developmental Disability*, 31(3), 180–182. <https://doi.org/10.1080/13668250600876400>
- American Association on Intellectual and Developmental Disabilities. (2021). *Definition of intellectual disability*. <https://www.aaid.org/intellectual-disability/definition>
- Atkins, L. (2016). Dis(en)abled: Legitimizing discriminatory practice in the name of inclusion? *British Journal of Special Education*, 43(1), 6–21.
<https://doi.org/10.1111/1467-8578.12123>
- Catala, A. (2020). Metaepistemic injustice and intellectual disability: A pluralist account of epistemic agency. *Ethical Theory and Moral Practice*, 23, 755–776.
<https://doi.org/10.1007/s10677-020-10120-0>
- Collins, H. (2018). Studies of expertise and experience. *Topoi*, 37, 67–77.
<https://doi.org/10.1007/s11245-016-9412-1>
- de Haas, C., Grace, J., Hope, J., & Nind, M. (2022). Doing research inclusively: Understanding what it means to do research with and alongside people with profound intellectual disabilities. *Social Sciences*, 11(4), 159.
<https://doi.org/10.3390/socsci11040159>
- Denzin, N. K. (2017). Critical qualitative inquiry. *Qualitative Inquiry*, 23(1), 8–16.
<https://doi.org/10.1177/1077800416681864>
- Santos, B.D. (2007). Beyond Abyssal Thinking: From Global Lines to Ecologies of Knowledges. *Canadian Parliamentary Review*, 30, 130-147.
<https://doi.org/10.4324/9781315634876-14>
- de Sousa Santos, B. (2014). *Epistemologies of the South: Justice against epistemicide*. Routledge.

- Elsen, I., Cunningham, B. J., & Campbell, W. (2018). Conducting participatory photography with children with disabilities: A literature review. *Disability and Rehabilitation, 41*(16), 1943–1954.
<https://doi.org/10.1080/09638288.2018.1457089>
- Fals Borda, O., & Rahman, M. A. (1991). *Action and knowledge: Breaking the monopoly with participatory action-research*. Apex Press.
- Fine, M. (2018). *Just research in contentious times: Widening the methodological imagination*. Teachers College Press.
- Fine, M., & Torre, M. E. (2021). *Essentials of critical participatory action research*. American Psychological Association. <https://doi.org/10.1037/0000241-000>
- Francis, G. L., Gross, J. M. S., Turnbull, A. P., & Turnbull, H. R. (2014). Understanding barriers to competitive employment: A family perspective. *Inclusion, 2*(1), 37–53.
<https://doi.org/10.1352/2326-6988-2.1.37>
- Friere, P. (1970). *Pedagogy of the oppressed*. Continuum International.
- Fyson, R., & Cromby, J. (2013). Human rights and ID in an era of “choice.” *Journal of Intellectual Disability Research, 57*(12), 1164–1172.
<https://doi.org/10.1111/j.1365-2788.2012.01641.x>
- Gaventa, J. (1991). Toward a knowledge democracy: Viewpoints on participatory research in north america. In O. Fals-Borda & M. A. Rahman (Eds.), *Action and knowledge: Breaking the monopoly with participatory action research* (pp. 121–131). Apex Press.
- hooks, b. (1984). *Feminist theory: From margin to center*. South End Press.
- Juritzen, T. I., Grimen, H., & Heggen, K. (2011). Protecting vulnerable research participants: A Foucault-inspired analysis of ethics committees. *Nursing Ethics, 18*(5), 640–650. <https://doi.org/10.1177/0969733011403807>
- Kennedy, J. M. (2005). Institutional researchers and institutional review boards. In P. D. Umbach (Ed.), *Survey research emerging issues: New Directions for Institutional Research*, Number 127 (1st ed., pp. 17–31). Jossey-Bass.
- Kim, J. H., Hughes, O. E., Demissie, S. A., Kunzier, T. J., Cheung, W. C., Monarrez, E. C., Burke, M. M., & Rossetti, Z. (2022). Lessons learned from research collaboration among people with and without developmental disabilities. *Intellectual and Developmental Disabilities, 60*(5), 405–415.
<https://doi.org/10.1352/1934-9556-60.5.405>

- Limes-Taylor Henderson, K., & Esposito, J. (2019). Using others in the nicest way possible: On colonial and academic practice(s), and an ethic of humility. *Qualitative Inquiry*, 25(9–10), 876–889. <https://doi.org/10.1177/1077800417743528>
- Linton S. (1998). *Claiming disability: Knowledge and identity*. NYU Press.
- McDonald, E. E., Kidney, C. A., & Patka, M. (2012). “You need to let your voice be heard”: Research participants’ views on research. *Journal of Intellectual Disability Research*, 57(3), 216–225. <https://doi.org/10.1111/j.1365-2788.2011.01527.x>
- McDonald, K. E., Conroy, N. E., & Olick, R. S. (2016). Is it worth it? Benefits in research with adults with intellectual disability. *Intellectual and Developmental Disability*, 54(6), 440–453. <https://doi.org/10.1352/1934-9556-54.6.440>
- Mills, C. W. (1997). *The racial contract*. Cornell University Press.
- Ming, J., Heung, S., Azenkot, S., & Vashistha, A. (2021, October). *Accept or address? Researchers’ perspective on response bias in accessibility research* (Article No. 20 1-13). ASSETS ’21: The 23rd International ACM SIGACCESS Conference on Computers and Accessibility. <https://doi.org/10.1145/3441852.3471216>
- Morgan, M. F., Cuskelly, M., & Moni, K. B. (2014). Unanticipated ethical issues in a participatory research project with individuals with intellectual disability. *Disability & Society*, 29(8), 1305–1318. <https://doi.org/10.1080/09687599.2014.934440>
- Nind, M., Chapman, R., Seale, J., & Tilley, L. (2016). The conundrum of training and capacity building for people with learning disabilities doing research. *Journal of Applied Research in Intellectual Disabilities*, 29(6), 542–551. <https://doi.org/10.1111/jar.12213>
- Nind, M., & Vinha, H. (2014). Doing research inclusively: Bridges to multiple possibilities in inclusive research. *British Journal of Learning Disabilities*, 42(2), 102–109. <https://doi.org/10.1111/blld.12013>
- Parsloe, S. M. (2015). Discourses of disability, narratives of community: Reclaiming an autistic identity online. *Journal of Applied Communication Research*, 43(3), 336–356. <https://doi.org/10.1080/00909882.2015.1052829>
- Patton, M. Q. (2015). *Qualitative research and evaluation methods* (4th ed.). Sage.
- Pillow, W. (2003). Confession, catharsis, or cure? Rethinking the uses of reflexivity as a methodological power in qualitative research. *International Journal of Qualitative*

- Studies in Education*, 16(2), 175–196.
<https://doi.org/10.1080/0951839032000060635>
- Reybold, L. E., Lammert, J. D., & Stribling, S. M. (2013). Participant selection as a conscious research method: Thinking forward and the deliberation of “emergent” findings. *Qualitative Research*, 13(6), 699–716.
<https://doi.org/10.1177/1468794112465634>
- Roy, A. (2017). *The ministry of utmost happiness*. Penguin Random House.
- Slee, R. (2019). Belonging in an age of exclusion. *International Journal of Inclusive Education*, 23(9), 909–922. <https://doi.org/10.1080/13603116.2019.1602366>
- Strnadová, I., & Walmsley, J. (2017). Peer-reviewed articles on inclusive research: Do co-researchers with intellectual disabilities have a voice? *Journal of Applied Research in Intellectual Disabilities*, 31(1), 132–141.
<https://doi.org/10.1111/jar.12378>
- Taylor, A. (2018). Knowledge citizens? Intellectual disability and the production of social meanings within educational research. *Harvard Educational Review*, 88(1), 1–25. <http://hepgjournals.org/doi/pdf/10.17763/1943-5045-88.1.1?code=hepg-site>
- Turnbull, H. R., & Turnbull, A. P. (2000). Newly in pursuit of an old philosophy: Rebalancing liberty, equality, and community. In M. L. Wehmeyer & J. Patton (Eds.), *Mental retardation in the 21st century* (pp. 413-430). PRO-ED.
- Walmsley, J., Strnadova, I., & Johnson, K. (2018). The added value of inclusive research. *Journal of Applied Research in Intellectual Disabilities*, 31(5), 751–759.
<https://doi.org/10.1111/jar.12431>
- Wolfensberger, W. (2000). A brief overview of Social Role Valorization. *Mental Retardation*, 38(2), 105–123. [https://doi.org/10.1352/0047-6765\(2000\)038](https://doi.org/10.1352/0047-6765(2000)038)
- Woodfield, C. L., & Freedman, J. E. (2021). Barriers to knowing and being known: Constructions of (in)competence in research. *Philosophical Inquiry in Education*, 28(2), 176–194. <https://files.eric.ed.gov/fulltext/EJ1314268.pdf>

Conclusions

The purpose of this dissertation was to explore inclusion at postsecondary education programs through qualitative participatory inquiry alongside eight individuals with IDD. This inquiry emerged from the historic and systemic lack of research which includes individuals with IDD as valued participants or co-researchers. This absence in research participation is particularly problematic as the surge of PSEs continues across the country.

Manuscript 1 explored the research question: What are the experiences of inclusion at postsecondary education programs through qualitative conversations and reflections on “what is inclusion?” Manuscript 2 builds off of Manuscript 1 and explores the research question: What are the recommendations of individuals with IDD for inclusive experiences at PSE? Manuscript 3 provides a reflection and critical self- study upon epistemology and methodological decisions made in an attempt to confront the traditional research cycle to engage in a more accessible and inclusive inquiry. Findings and reflections from this study highlight six key themes related to inclusion at the postsecondary level, recommendations for choice as a means to increase inclusive experiences, and the importance of participatory inquiry to include individuals traditionally left out of the research process.

When considering these findings holistically, there are numerous implications for research and practice. This study highlights the importance of individuals with IDD informing research, policy, and practice through sharing inclusive experiences. Further, this study provides an example of an approach to research which centered the participants and remained flexible in order to be accessible and meaningful to the research group.

As discussed in Manuscript 1, the complexity of inclusion and inclusive experiences shared by EFR members provides critical insight for future researchers, practitioners, and students with IDD who may be considering college as a next step. Six themes from Manuscript 1 help define inclusion as: (a) being with specific people, not places; (b) friends that “get me”; (c) making choices; (d) having opportunities and being granted permission; (e) having support; and (f) a feeling you know when you feel it. It is clear that inclusion is a multifaceted concept defined by individuals in different ways. One major implication is that individuals with IDD need to be at the center of designing and influencing their postsecondary and adulthood experiences instead of family members or professionals. In practice, PSEs should offer a variety of educational and social opportunities and consider the input of students in program design. Specifically, while the goal is integration on college campuses, PSEs should be mindful of the importance of disability-centric spaces which may feel familiar or safe, and lead to students with IDD feeling included. Implications for research also center the individual with IDD. Future research should focus on increasing the number of studies which focus on the perspectives of individuals with IDD, and not relying on proxies. This requires additional observation of strategies which support individuals’ access or participation in

research (e.g., visual strategies, story-sharing, in-person settings). Additionally, future research should focus on specific areas or periods of life to investigate perspectives of inclusion as it may lead to broader generalizations of this murky concept. This may also lead to better understanding of inclusive experiences and PSE participation on life outcomes (e.g., independent living, employment, satisfaction with relationships). Primary limitations outlined in Manuscript 1 include the size of the research group, the use of self-disclosure of disability labels, lack of in-person meetings due to COVID-19 and the corresponding requirement for technology, and the participatory design.

As discussed in Manuscript 2, implications related to choice and individuals with IDD are numerous. EFR members recommend choices in the following areas that can increase inclusive experiences at college: (a) choice in courses, keep general access open but allow choice of when, where, and with whom; (b) choice in help, allow choice in how it is received; and (c) social life, allow choice in friendships and activities. The importance of choice as an implication extends beyond the PSE setting. In practice, professionals and stakeholders should be explicitly embedding choice into curriculum or programming (e.g., daily, weekly, or across the semester) to increase the opportunities for individuals or students to make choices. Additionally, supported decision-making models should be adopted and utilized to support self-determination and exercising choice. Further, these practices should take place long before an individual turns 18 or enters postsecondary settings. Student support team members (i.e., family members, teachers, counselors) should actively seek ways to insert choice in daily life. Professionals also need to consider the impact of forced choices or nonchoices on student independence and

autonomy. Utilizing frameworks which help to assess risk may guide programs into allowing students to safely fail or make mistakes as part of their growth and development, particularly while at college. Implications for research include focusing on choice and improving choice-making procedures and strategies for individuals with IDD. Future research should aim to further develop supported decision-making protocols in daily living settings, building off of transition-focused or person-centered planning protocols. Additionally, research should explore choices made in specific stages of life to better understand best practices in preparing adults with IDD to enter communities after high school or college. Above all, implications for future research are to continue seeking the expert perspective of intellectuals with IDD when investigating PSEs and/or inclusive experiences. Primary limitations outlined include the length of study and virtual format due to COVID-19, the participatory and flexible design with participants engaging in primary analysis, and the lack of generalizability of findings due to the qualitative nature of the design.

Manuscript 3 is a response to and reflection of the methodological decisions and actions taken during the study. Implications shared in Manuscript 3's reflections call for a closer examination and deeper critique of the methodological decisions, returning to the EFR collective for next steps in the research agenda, and considerations for future research.

Closer examination of the research study may provide additional critique or insight into barriers to knowledge production, threats to epistemic justice, and researcher misuse of power. Utilizing tools such as reconstructive horizon analysis (RHA) can

identify specific situations of power dynamics or threats to validity which impacted participation, or the potential of stories being shared. Additionally, closer examination of researcher–participant communication patterns may identify acts of ableism or acquiescence which consistently bars individuals with IDD from participating in meaningful research or being recognized as valued research partners.

A major implication and call for action in Manuscript 3 is the importance of returning to the EFR collective. Notably, the EFR group suggested creating announcements and videos on social media to inspire more individuals with disabilities to share their stories and provide advice to future college students. This is an unmet research collective goal, and should be prioritized in the name of equitable research.

Future research aiming for inclusivity needs to be accessible at all levels or steps of the research cycle. This includes synthesizing research and critically examining how we got to where we are now. More work needs to be done to make texts accessible and meaningful to democratize knowledge production as research teams embark on literature reviews. Even as I approached the required literature review and demonstration of breadth and depth of knowledge, I was confronted with the discrepancies between my commitment to who and what knowledge is considered expert, or matters and therefore who or what needs to be referenced. In my work I stand on the backs of the greats in the field, many of whom, like me, can never claim expertise in knowing disability but instead lean on practice and research, which again can be debated as to the level of “goodness.” Not citing or following a seminal work is often seen as lacking breadth and depth, but

these works were not written for EFR. The methods and theory are not accessible; how can my work include if I promote what never has been inclusive or accessible?

Next, engaging in participatory or inclusive research needs to be a transparent process, and future research should include participants or co-researchers earlier in that process. Community groups should form before a research question is posed, in order to accurately represent the voice and needs of the community. Future research should also incorporate more participant and co-researcher ideas to strengthen the findings of the work as well as build a more inclusive research community.

Confronting systems of power and inequity can and must be done through collective and participatory efforts. The monopoly on knowledge (therefore power) held by nondisabled outsiders in positions of power through research and political institutions perpetuates the epistemicide of individuals with IDD. The paucity of research with, for, and by individuals with IDD perpetuates policies and programming, often missing critical considerations which can only be informed by the experts. This requires a reframing of the conceptualization of research as a whole—to include who can be a researcher, what forms can a study design take, what counts as data, who can analyze or add to meaning, and whose voice is represented in sharing of knowledge. Doing so will contribute to a disruption in the status quo of disability-related research and democratize knowledge production at the academia level, but equally at the societal level within communities.

General Appendix

IRB Approval Letter



Office of Research Integrity and Assurance

Research Hall, 4400 University Drive, MS 6D5, Fairfax, Virginia 22030
Phone: 703-993-5445; Fax: 703-993-9590

DATE: October 13, 2020

TO: Grace Francis, PhD
FROM: George Mason University IRB

Project Title: [1663508-1] Exploring Inclusion with Individuals with Intellectual and Developmental Disabilities: A Participatory Inquiry Dissertation

SUBMISSION TYPE: New Project

ACTION: APPROVED
APPROVAL DATE: October 13, 2020
REVIEW TYPE: Expedited Review

REVIEW TYPE: Expedited review category #7

Thank you for your submission of New Project materials for this project. The George Mason University IRB has APPROVED your submission. This submission has received Expedited Review based on applicable federal regulations.

You are required to follow the George Mason University Covid-19 research continuity of operations guidance. You may not begin or resume any face-to-face interactions with human subjects until (i) Mason has generally authorized the types of activities you will conduct, or (ii) you have received advance written authorization to do so from Mason's Research Review Committee. In all cases, all safeguards for face-to-face contact that are required by Mason's COVID policies and procedures must be followed.

Please remember that all research must be conducted as described in the submitted materials.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding followed by a signed consent form unless the IRB has waived the requirement for a signature on the consent form or has waived the requirement for a consent process. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Federal regulations require that each participant receives a copy of the consent document.

Please note that any revision to previously approved materials must be approved by the IRB prior to initiation. Please use the appropriate revision forms for this procedure.

All UNANTICIPATED PROBLEMS involving risks to subjects or others and SERIOUS and UNEXPECTED adverse events must be reported promptly to the IRB office. Please use the appropriate reporting forms for this procedure. All FDA and sponsor reporting requirements should also be followed (if applicable).

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to the IRB.

This study does not have an expiration date but you will receive an annual reminder regarding future requirements.

Please note that all research records must be retained for a minimum of five years, or as described in your submission, after the completion of the project.

Please note that department or other approvals may be required to conduct your research in addition to IRB approval.

If you have any questions, please contact Katie Brooks at (703) 993-4121 or kbrook14@gmu.edu. Please include your project title and reference number in all correspondence with this committee.

GMU IRB Standard Operating Procedures can be found here: <https://oria.gmu.edu/topics-of-interest/human-subjects/>

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within George Mason University IRB's records.

General References

- American Association on Intellectual and Developmental Disabilities. (2021). *Definition of intellectual disability*. <https://www.aaid.org/intellectual-disability/definition>
- American Association on Intellectual and Developmental Disabilities. (2020). *Inclusion: Joint position statement of AAIDD and the Arc*. <https://www.aaid.org/news-policy/policy/position-statements/inclusion>
- Americans With Disabilities Act of 1990, 42 U.S.C. § 12101 *et seq.* (1990).
- Education for All Handicapped Children Act, Pub. L. No. 94-142, § 601(c) (1975).
- Francis, G. L., Reed, A. S., & Howard, M. E. (2020). Interactions with and between families and professionals in college: Perspectives of young adults with intellectual and developmental disabilities. *Inclusion*, 8(2), 163–179. <https://doi.org/10.1352/2326-6988-8.2.163>
- Grigal, M., & Hart, D. (2010). *Think College: Postsecondary education options for students with intellectual disabilities*. Paul H. Brookes.
- Grigal, M., Hart, D., Papay, C., & Smith, F. (2018). *Year two program data summary (2016-2017) of the TPSID model demonstration projects*. University of Massachusetts Boston, Institute for Community Inclusion.
- Grigal, M., Hart, D., Smith, F. A., Domin, D., Sulewski, J., & Weir, C. (2014). *Think College National Coordinating Center: Annual report on the transition and postsecondary programs for students with intellectual disabilities (2012–2013)*. University of Massachusetts Boston, Institute for Community Inclusion.
- Institute on Disability. (2018). *Disability statistics annual report*. Rehabilitation Research and Training Center on Disability Statistics and Demographics. https://disabilitycompendium.org/sites/default/files/user-uploads/2016_AnnualReport.pdf
- Keefe, C. H., & Davis, R. (1998). Inclusion means. *NASSP Bulletin*, 82(594), 54–64. <https://doi.org/10.1177/019263659808259409>

- Martin, J. E., & Williams-Diehm, K. (2013). Student engagement and leadership of the transition planning process. *Career Development and Transition for Exceptional Individuals*, 36, 43–50. <https://doi.org/10.1177/2165143413476545>
- Officer, A., & Groce, N. E. (2009). Key concepts in disability. *Lancet*, 374, 1795–1796. [https://doi.org/10.1016/S0140\(09\)61527-0](https://doi.org/10.1016/S0140(09)61527-0)
- Olmstead v. L.C., 527 U.S. 581 (1999).
- Paiewonsky, M. (2011). Hitting the reset button on education: Student reports on going to college. *Career Development for Exceptional Individuals*, 34(1), 31–44. <https://doi.org/10.1177/0885728811399277>
- Prohn, S. (2014). *A grounded theory of social inclusion for postsecondary education students with intellectual disability* (UMI No1 3690350) [Doctoral dissertation]. ProQuest Dissertations and Theses.
- Slee, R. (2019). Belonging in an age of exclusion. *International Journal of Inclusive Education*, 23(9), 909–922. <https://doi.org/10.1080/13603116.2019.1602366>
- Walte, S., Cushing, L. S., Athamanah, L. S., & Posey, K. (2017). Seeking the perspectives of transition-age students with significant disabilities in research since 1990. *Division on Autism and Developmental Disabilities Online Journal*, 4, 47–62.

Biography

Alexandra S. Reed received her Bachelor of Arts in Psychology and Liberal Arts from Pepperdine University in 2011. She received her Master of Education in Special Education from George Mason University in 2012.