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"And then you can prove them wrong": The college experiences of students with intellectual and developmental disability labels

Katherine Vroman
Syracuse University

Abstract

This dissertation chronicles the college experiences of students with intellectual and developmental disability labels enrolled in an inclusive postsecondary program, as told by them. Using student-generated digital photographs as visual supports around which to organize focus group conversations, I employ a participatory, phenomenological methodology to garner and represent the students' experiences. The study design, and data collection are informed by both feminist and Disability Studies epistemological and theoretical frameworks, while the analysis foregrounds Disability Studies, seeking to privilege and center the voices of a population of students who have been largely left out of scholarship to date. This study lives within a cultural and historical moment where students with intellectual and developmental disability labels are steadily gaining access to postsecondary education spaces via alternative pathway programs, thus necessitating close, consistent investigation of what happens therein. Findings highlight the integral, though not uncomplicated role of the inclusive postsecondary education program structures in facilitating students' access to and participation in social and academic facets of campus life, friendship dynamics between students with and without disabilities, and the presence of support staff in students' lives. Additionally, this dissertation foregrounds key methodological questions about how to deliver on the promise of inclusive, participatory inquiry and exposes tensions around issues of informed consent, communication, and support for participants with intellectual and developmental disability labels. This work invites inclusive postsecondary education practitioners, Disability Studies scholars, self-advocates, and their allies to explore the contours and conflicts of intellectual disability identity, affinity, and college membership, challenging us all to honor student experiences while continually bending towards a future we have perhaps not yet imagined.

"And then you can prove them wrong": The College Experiences of Students with Intellectual

and Developmental Disability Labels

By

Katherine M. J. Vroman

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For Hugo Brace, the most important work I'll ever do.

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mother in their dissertation or that they wore their father's regalia to commencement—I understand these realities of my life as an honor.

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Chapter 1

Introduction

I was born at college—in State College, Pennsylvania, to be precise—home to the main campus of Penn State University and its approximately 50,000 students. My parents were in the final stages of their doctoral programs and were idealistic enough to start a family before defending their dissertations—who, if given a choice, would do that? As academics, my family relocated based on finding the right university jobs, finally settling in Dover, New Hampshire when I was two years old and my sister was six months. My father was a professor of kinesiology at The University of New Hampshire and my mother started out as a project assistant at the Institute on Disability, working on a small grant that trained parents and professionals from six schools across the state to foster more inclusive practices for students with disabilities. Eventually, my father moved to what he facetiously called "the dark side" of administration while my mother wrote federal grants every three years to fund her own and others' positions. She traveled a few times a year to national conferences and, in addition to the packs of Carefree sugarless gum she bought at the airport (in a candy-deprived household this was our Christmas), brought home conference t-shirts for my sister and me. One conference shirt from TASH (formerly The Association for the Severely Handicapped) was well-worn, becoming a favorite nightshirt or swimsuit cover-up—it was neon teal with "Schools Are For All Children" written on the front in white letters. The inclusive education movement had really begun to gain momentum in the early 1990s and my mother joined efforts of parents of children with disabilities, including the most significant disabilities, to make the case that segregated special education classrooms in K-12 schooling were not only ethically questionable, but resulted in poorer outcomes for all stakeholders. In the decades that followed, a growing body of research

supported what began as a moral imperative, evidencing better educational and social outcomes for students with and without disabilities who were educated in inclusive classrooms, and increasing the likelihood that students with disabilities would pursue some kind of postsecondary education (Cole, Waldron, & Majd, 2004; Jackson, Ryndak, & Wehmeyer, 2008, 2009, 2011; Jorgensen, McSheehan, & Sonnenmeier, 2010). However, like most children, unless your parents have an easily-understandable profession like nurse, mechanic, or police officer, you don't really know what they do for a living. And so, while we didn't really know how much my dad saw universities as sites of great potential, or that my mother was becoming regarded as a pioneer in inclusive education, we did know that they both pushed for us to be placed in Mr. McKenney's fifth-grade classroom because he pushed for Mrs. Stratton's special education classroom to join ours for the majority of the day. We did know how irate they became when my sister's tenth grade English teacher lamented how she "wasn't a 'good student' like her sister, Katherine." We did know that the "r-word" was the worst swear you could possibly utter. Every year we watched my dad get ready to attend UNH's commencement ceremony and tried on his funny hat and velvet-edged robe, and saw more and more books on our shelves that had my mom's name on the bindings. I suppose it's no surprise then, that not only did I end up pursuing doctoral work, effectively ensuring that I will never really leave a university, but the culmination of this doctoral work investigates the very institution that has shaped my entire life: College.

Since beginning this doctoral program journey, I always thought I'd research and write my "opus." I'm not quite sure where this rose-colored-view of the dissertation process came from—my parents defended their dissertations (written on typewriters for goodness sake!) in May and November of 1982, when I was not yet a year old. And yet, throughout my doctoral program I had been unable to shake the lure of sentiments like this one, that Teresa Brenna posed

as a question (and, I assume, a challenge) to Linda Alcoff: "Have you ever written precisely and exactly what you truly think and believe, without editing yourself down? Have you ever written not for the present-day audience but for the future?" (as cited in Alcoff, 2003, p. 12). As I was steeped within these expectations along with the graduate school cultural norms of "*Your* question has to be something *you* are dying to know the answer to!" "Pick the one thing *you're* most passionate about," or "Follow *your* burning question," that I stalled. This messaging felt incompatible with the work that I was doing, and that I became good at: working as a graduate research assistant at The Institute for Communication and Inclusion (ICI). The ICI framed its mission around supporting individuals with complex communication needs to fully participate in their schools and communities by conducting research, providing training and technical assistance to families, educators and agency staff and doing direct communication support work. Our staff and research team prided itself in employing research methods that were almost always flexibly qualitative with a strong bent towards facilitating participants' expressions of voice, no matter how that voice manifested. When we, as a group of individuals that, by and large, did not claim disability identities, were asked questions during workshops or trainings about *our* advice for specific communication supports and services, we usually deferred to the self-advocates in the room. And they were always in the room. However, for many of the individuals who came through the doors of the ICI who communicated via non-speaking means and often carried multiple disability labels, it was never assumed that their academic journeys would lead them to postsecondary education, in fact, it was often the opposite. Most of my friends from the ICI had to constantly prove their membership in general education classrooms throughout their K-12 careers, despite federal Individuals with Disabilities Education Improvement Act (IDEIA, 2004) legislation that theoretically sets general education as the default placement for all students.

Thus, for individuals with intellectual or developmental disability labels, or disabilities that manifest in complex communication needs, the idea of going to college is not a "given" but rather a dream. In fact, the very nature of postsecondary education is exclusive, and admits students based on traditional measures of intelligence or potential such as SAT scores and academic records, effectively deciding who college is *for*, and who it is not for. However, in the past decade, a confluence of circumstances including changing attitudes about disability, legislative support and sustained parental advocacy has fostered a new climate in which postsecondary education experiences are becoming realities for increasing numbers of students with disabilities, including intellectual disabilities. Accommodating student diversity now includes issues relating to disability, as the broader conversation about education as a civil right has steadily extended to encompass cultural and identity groups who have traditionally been excluded. As this new population of students joins the ranks of America's college-going population, colleges and universities are tasked with garnering and documenting their experiences and, as the literature reviewed for this dissertation will show, many come up short. While there is ample attention and resources devoted to assessing the experiences, levels of satisfaction, and post-school outcomes of traditionally-enrolled students so that colleges can tailor their program offerings to meet the niche needs of their target student audience, the perspectives of students with intellectual and developmental disability labels are largely absent from similar program evaluation data. This is perhaps not surprising, as the voices of individuals with intellectual disabilities are largely absent from most research about their lives, often citing methodological challenges as the reason for their exclusion. And so, as I moved closer to a dissertation focus, my initial research into inclusive postsecondary education scholarship and practice revealed that the field may not be methodologically equipped to answer its most salient

question, namely: What *are* the college experiences of students with intellectual and developmental disabilities?

Though this may feel like a bit of a navel-gazing introduction, my intent is rather to share the "ah ha" moment that had taken five years to show itself: my dissertation shouldn't be about what *I'm* most passionate about, or *my* burning question, or what *I'm* most interested in finding an answer to. It shouldn't be about me, and at the same time, my own history and genealogy always seemed to lead me back to college—it's an institution that, with all its faults, I care about, and my participants cared about. Recognizing that there was a danger of telling a limited, narrow story if I were the sole decision-maker in developing this study, I ultimately decided to begin at the beginning and ask the students themselves: "So, tell me about college."

The Problem

It's a fair claim that in the climate of neoliberalism in which we find ourselves, the middle-class aspiration of "college going culture" remains omnipresent. Throughout politics, media, and popular culture, college is still held up as a great equalizer—the silver bullet for tackling inequality and leveling the proverbial playing field for all Americans. Even though institutions of higher education are inherently resistant to major structural changes that undermine the epistemic power of traditionally dominant groups and thus function in practice to exclude, marginalize or potentially discredit diverse or alternative knowledge and knowers, there is, as Elster (2016) notes, "the tendency of the oppressed and exploited classes in a society to believe in the justice of the social order that oppressed them" (Elster 2016, p. 26.) For persons with disabilities or other traditionally underrepresented groups, The Academy still emits an intoxicating, enticing force: historical struggles for equitable participation in spaces of knowledge production and the corresponding cultural and intellectual capital that characterizes

higher education credentials still possesses a legitimizing potential to achieve epistemic justice that, hopefully, leads to political, social and personal emancipation. Though participation of students with disabilities in postsecondary education generally is on the rise as I will discuss in greater detail in Chapter 2, the experiences of students with intellectual and developmental disability labels (IDD) are harder to access. As noted in a 2004 report from The Institute for Higher Education Policy, since attending higher education is voluntary and not compulsory, all students, including those with disabilities, must meet the often-stringent academic admissions standards. Federal IDEIA legislation that guarantees students with disabilities access to and participation in K-12 public schooling does not apply to postsecondary education:

> 'Zero rejects' does not apply. It is also commonplace for students to be terminated at a higher education institution, most commonly for substandard academic performance. 'No cessation of services' also does not apply in higher education. Thus, in general, attention must be focused on providing higher educational opportunities for those persons with disabilities who can meet the academic standards for admission, progress, and graduation, who are, in short, 'college qualified.' Limiting the universe to the college qualified generally excludes those secondary school students with disabilities who have significant mental retardation or other developmental impairments[1] that leave them without the intellectual capacity to succeed academically in higher education (Wolanin & Steele, 2004, p. xv-xvi).

However, in the decade since the abovementioned report was released, students with intellectual and developmental disability labels (IDD) have been afforded greater access to

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[1] Beginning on page 13, I discuss the language and terminology decisions I made in this dissertation.

postsecondary education spaces through a variety of inroads, thus challenging the dominant paradigm of what it means to be a college student. Though there exists significant variability in the profile of not only the students but the programs in which they participate and how their participation is supported, an increasing body of scholarly literature is attempting to describe this multi-faceted phenomenon. Therefore, this dissertation seeks to elicit the postsecondary education experiences of students with IDD labels to get at "what *they* are experiencing, how *they* interpret their experiences, and how *they* themselves structure the social world in which they live" (original emphasis, Psathas, 1973, as cited in Bogdan & Biklen, 1992, p. 32). The plethora of available studies that elicit experiences of typical college students (e.g. students without disabilities) present data that allow institutions of higher education to be responsive to student needs and make targeted improvements. Metrics such as Your First College Year (Ruiz, Sharkness, Kelley, DeAngleo, & Pryor, 2010), the National Survey of Student Engagement (NSSE, 2009), the Community College Survey of Student Engagement (Center for Community College Student Engagement [CCCSC], 2009), and The American Freshman: National Norms (Pryor, Hurtado, DeAngelo, Palucki Blake, & Tran, 2010) all seek to garner students' college experiences. However, these surveys do not include the experiences of students with disabilities, specifically IDD labels, because they are most often enrolled in non-traditional programs or the surveys are inaccessible to them, necessitating alternative ways to elicit their perspectives (Paeiwonsky, 2011).

Research questions

This study is guided by the following research questions: 1) How do students with intellectual and developmental disability (IDD) labels describe and represent their college experiences? 2) What does inquiring into the experiences of college students with IDD labels

teach us about inclusive postsecondary education? And, 3) What does inquiring into the experiences of college students with IDD labels teach us about doing research with individuals with IDD labels? Here, "us" refers to Disability Studies scholars and practitioners and those working in inclusive postsecondary education settings.

Theoretical Frameworks

Disability Studies

This dissertation assumed a Disability Studies-informed approach to study design, data collection and analysis. In doing so, my goal was to reimagine disability beyond medical or diagnostic labels and their accompanying assumptions, and instead presume the competence of my participants not only as informants but also as college students, and thus knowledge-makers (Biklen, 2005). Following the precedent for social change set in motion by the American Civil Rights Movement and a national culture imbued with an increasing call for equality and justice, the Disability Rights Movement formally emerged in the 1970s and 1980s, as individuals with disabilities began to question and challenge the systems of oppression in their own lives (Charlton, 1998; Fleischer & Zames, 2011.) Scaffolded by ideals of full participation and equitable citizenship and the British-born "social model" of disability, people with disabilities in the U.S. began to situate disability in "the environment" rather than "the body," thus necessitating "not individual medical treatment [or other forms of "intervention"] but changes in society" (Siebers, 2008, p. 73).

As a theoretical and academic complement to this growing movement, Disability Studies evolved as a framework that coalesced the lived, shared experiences of people with disabilities and sought to both identify and combat their marginalization and oppression. The interdisciplinary efforts of scholars and activists established foundational theory and literature,

interpreting the cultural experience of disability as not just medical malady or bodily impairment, but social construction (Ferguson & Nusbaum, 2012; Fleischer & Zames, 2011; Linton, 1998; Oliver, 1990). As policymakers, educators, and direct-service providers began to adopt Disability Studies frameworks or at least consider alternative explanations for what might be "going on," the understanding of their work started to veer away from the politics of care, cure and exclusion, and towards considering disability as another manifestation of difference (Linton, 1998; Shakespeare, 1996.)

Disability Studies is a counter-narrative to purely pathological understandings of bodily difference, and is no longer "emerging" or "burgeoning" as it has been characterized in much of the literature in the late 1990s to early 2000s (Davis 1995; Garland-Thomson, 1997; Erevelles, 2000; Ware, 2001) but "flourishing" (Garland-Thomson, 2014). Scholars in the field acknowledge the ubiquitous internal diversity and divergence that accompanies this flourishing (Jarman & Kafer, 2014) noting the emergence of various "critical threads" of Disability Studies that each bring a unique lens to their analyses (Garland-Thomson, 2014). Erevelles (2014) further complicates the character of this field, noting its tenuous and perhaps contradictory place "at the apprehensive boundaries between academia and activism" (Accountability/Disability Justice section, para. 3). However, within this liminal philosophical space, Erevelles (2014) observes how Disability Studies has the potential to: "foreground the material conditions that can enable academia and activism to work symbiotically in the struggle for unexpected and evocative possibilities of living productive and celebrated lives" (Accountability/Disability Justice section, para. 5). Therefore, Disability Studies proved a useful, but not uncomplicated theoretical tool with which to complicate the data herein. In Chapter 6, I discuss how interpreting this dissertation's findings through a Disability Studies lens told a different story than that narrated

by the participants. That is, a Disability Studies reading of these data offered new, different, and sometimes contradictory understandings of the college experiences of students with IDD labels.

Feminist Theory and Practice

In selecting an additional theoretical and methodological framework to inform this study, I found natural points of congruence between feminist theory and practice and research with individuals with IDD labels. Disability Studies scholars have drawn from feminist principles of excavating previously suppressed "voices" and valuing participants' lived experiences, and thus there are myriad examples of philosophical and practical overlap between these paradigms (Broun & Heshusius, 2004; Morris, 1991; Oakley, 1981; Reinharz, 1992; Rose, 1994). Broun & Heshusius (2004) note that, "feminist research stresses collaboration and the mutual construction of knowledge through shared perceptions, experiences and concerns" (The Evolution of the Methodological Choices section, para. 5) while Morris (1991) stresses that the feminist principle of "the personal is political" is particularly salient to the experience of disablement (p. 183). Additionally, feminist standpoint theory helped me negotiate the tensions that arose when my participants narrated their own experiences in ways that sometimes differed from what I understood as "fact" or "truth." Haraway (1988) and others (see Anzaldua, 1987; Hartsock, 1998) offer that that there is no one truth, but multiple, situated knowledges to be gleaned from the "vantage points of the subjugated" (p. 583). Throughout my analysis, I attempted to honor the experiences of my participants while being mindful that "the positionings of the subjugated are not exempt from critical reexamination, decoding, deconstruction and interpretation" (Haraway, 1988, p. 584). Thus, also approaching this dissertation with a bent towards feminist theory reminded me to always privilege, but not romanticize, my participants' voices, and informed the methodological decisions I made throughout.

While perhaps initially focused on centering the experiences of women, Devault's (1999) work can inform research with other historically marginalized populations such as people with disabilities (Ashby, 2011; Biklen & Casella, 2007; Petersen, 2011). Devault (1999) notes that for her, as a qualitative researcher, feminism provided a useful lens with which to question and resist "business as usual" and consider her own marginality (in her case, within academia) to understand that of others (p. 17). For Devault (1999) adopting a feminist-informed methodology meant not only seeking the lived experiences of her participants, but also contemplating how those experiences are shaped by societal systems of oppression. As Ashby (2011) built on Devault's work, "whether those systems are oppressive for their inherent sexism, classism, heterosexism, and racism or, in the case of my research, ableism, feminist concerns with power and voice are clearly relevant and useful" (Problematizing Voice and Method section, para. 2). In complicating the taken-for-granted assumption of interview research as "talking with people," Devault & Gross (2007) note the "fascinating complexity of human talk" that feminist methodologies can begin to expose:

> …The flexibility and productive powers of language; the subtle shades of meaning conveyed through nuances of speech, gesture and expression; issues of translation; the ineluctable locatedness of any moment or stretch of talk; the specialized vocabularies of particular settings or groups; the organizing effects of format and genre; the injuries and uses of silence; the challenges inherent in listening and so on (p. 173).

And yet though Disability Studies researchers can apply the principles of feminist theory to the experiences of disability, there exists, as Devault & Gross (2007) note, "relatively little writing on disability issues in feminist research," citing the historical absence of people with disabilities from academic disciplines broadly (p. 180). Despite this dearth in scholarship that

intersects the worlds of feminism and Disability Studies, Devault & Gross (2007) suggest ways in which "ability structures interview encounters": "Most scholarship on interviewing presumes an able-bodied researcher and is geared towards an able-bodied audience. Interview techniques are designed with particular verbal and cognitive capacities in mind, assuming a relatively easy back-and-forth between interviewer and interviewee" (p. 180). While calling for the need for additional scholarship in this arena, Devault & Gross (2007) suggest that "the more important question is how to organize interviews so as to produce more truly collaborative encounters, whatever the identities or the commitments of participants" (p. 180). The values of feminist theory and practice guided my data collection process in terms of how I sought to facilitate focus groups and how, upon writing post-focus group memos, I made specific methodological decisions to facilitate the students' participation and to continually follow their leads. While feminist theory and practice informed the study design and the data collection process, it did not figure prominently in my analysis. I hope, as Silvers (2015) does, that this feminist, critical, political project will contribute to, "acknowledging the range of atypical (for humans) ways of knowing [and] reveal a heretofore unimagined richness in what humans can know the world is like." (Silvers, 2015, Feminist Epistemology and Disability Standpoints section, para. 12.)

Phenomenology

This study adopted a phenomenological stance towards study design, implementation and analysis, rejecting positivist notions that seek out one ultimate "truth," in favor of focusing on the "desires and beliefs that shape the activities of individuals within specific cultural contexts" (Tefera, 2011, p. 51). It recognizes that we are all selective in how we narrate our own stories and represent our own experiences, allowing for multiple, situated truths to exist in the students' stories (Haraway, 1988). Specifically, in this Disability Studies inquiry that errs on the side of

the social model of disability that locates disability in the environment rather than in the body

(Oliver, 1990), my endeavor was to look at how individuals interact with structures, processes,

institutions and environments that either exacerbate barriers or facilitate access (Biklen, 2005).

My role as researcher meant that I often had to wear two hats throughout this inquiry as the

person who was creating the necessary conditions under which my participants could collect and

analyze their own data, while also collecting and analyzing data about the process itself and the

meaning my participants were making. Thus, phenomenology allowed me to zoom in on the

socially-constructed world and seeks to understand how my participants made meaning within it

(Bogdan & Biklen, 2007; Creswell, 2012; Denzin & Lincoln, 2007; McPhail 1995; Moustakas,

1994). Students with intellectual and developmental disabilities are steadily moving into

postsecondary education spaces, and yet as the literature demonstrates in the next chapter, there

is little consensus as to not only what they are experiencing but what constitutes "inclusive"

postsecondary education. Approaching my data from a phenomenological standpoint started with

my participants' embodied subjectivities (Levering, 2006) and sought to draw from their

experiential knowledge to ask how they understood their shared phenomenon, namely, accessing

postsecondary education for the first time (Creswell, 2013; Denzin & Lincoln, 2008; Moustakas,

1994).

Terminology

Labeling individuals with disabilities is fraught with ideological, political and material

implications that can both empower and further marginalize the bodies and experiences they are

intending to describe. There is a palpable and legitimate tension between claiming disability

labels as identities rooted in pride and affinity, and resisting these same disability labels that have

historically served to stigmatize and marginalize. However, the scholarship upon which this

study builds utilizes generally accepted terminology that warrants definition.

Postsecondary Education (PSE)

Postsecondary Education (PSE) refers to "any type of school or training beyond the high school level (i.e., community college, four-year university, vocational training program)" (Think College, 2016.)

Intellectual Disability (ID)

"According to the AAIDD, the term 'Intellectual disability" is "characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18" (AAIDD, accessed from: http://www.aamr.org/content_100.cfm?navID=21). This term was also used in the Higher Education Opportunity Act (HEOA) of 2008, where students with ID are defined as follows: "The term "student with an intellectual disability" means a student (a) with mental retardation or a cognitive impairment, characterized by significant limitations in (i) intellectual and cognitive functioning; and (ii) adaptive behavior as expressed in conceptual, social, and practical adaptive skills; and (b) who is currently, or was formerly, eligible for a free appropriate public education under the Individuals with Disabilities Education Act (HEOA, 2008). The HEOA definition may be open to interpretation and becomes a challenge for students who have various other disability labels such as those students who are on the autism spectrum" (Grigal & Hart, 2009).

Developmental Disability (DD)

"'Developmental Disabilities' is an umbrella term that includes intellectual disability but also includes other disabilities that are apparent during childhood. Developmental disabilities are

severe chronic disabilities that can be cognitive or physical or both. The disabilities appear

before the age of 22 and are likely to be lifelong. Some developmental disabilities are largely

physical issues, such as cerebral palsy or epilepsy. Some individuals may have a condition that

includes a physical and intellectual disability, for example Down syndrome or fetal alcohol

syndrome." (AAIDD, accessed, September 4, 2016 from http://aaidd.org/intellectual-

disability/definition/faqs-on-intellectual-disability#.V8whnngTWS0)

Autism

In 2013, the American Psychiatric Association published the fifth edition of the

Diagnostic and Statistical Manual of Mental Disorders, commonly referred to as the "DSM-5,"

with a new, umbrella diagnosis of "autism spectrum disorder" (ASD), rather than previously

separate labels of autism, Asperger's syndrome, and pervasive developmental disorder (not

otherwise specified) or "PDD-NOS." Individuals with ASD are described as having "persistent

deficits in social communication and restrictive, repetitive patterns of behavior, interests or

activities" (American Psychiatric Association, 2013). Those with ASD may or may not also have

intellectual and/or developmental disabilities.

Though the definitions above locate disability within the individual and frame disability

as deficiency of mind and body, students that carry these labels reside at an ironic nexus of

needing the label to qualify for supports and services in schooling, and sometimes

simultaneously rejecting the label as all-encompassing of who they are as people (Davis, 1995;

Gallagher, Connor & Ferri, 2014; Linton, 1998; Oliver, 1996). Thus, as this study sought to build

on literature across fields of study with varying traditions of terminology, it also boasted an at-

times ambiguous relationship with the categories of disability outlined above. Therefore, to detail

a fuller picture of the scholarship about postsecondary education experiences for students with

IDD labels, literature that focused on various permutations of the "IDD" label was considered, including: Intellectual disability (ID), Intellectual and developmental disability (IDD), and Autism or Autism Spectrum Disorder (ASD). In reviewing the literature from a methodological standpoint and discussing the promise and limitations of qualitative research approaches, it warranted including "autism" as a search term, if only to broaden the pool of currently available scholarship. Additionally, many of the challenges of qualitative methods (i.e., issues of communication and voice, presumptions of competence and informed consent) remain consistent when considering individuals with intellectual disability labels and autism, and will be discussed later.

Throughout this work I most often use the term "students with intellectual and developmental disability labels" or "students with IDD labels," to describe my participants. I acknowledge that though they might not define themselves in this way (as will be discussed later), their membership in this broad category is part of what ultimately afforded them access into the Alma Mater Program, my research site. I added "labels" to this terminology to acknowledge my Disability Studies epistemological orientation and communicate a guiding philosophy and practice that understands intellectual disability as a social construction and not an immutable trait (Kliewer, Biklen & Petersen, 2015).

Positionality

As in other social justice-informed inquiry that seeks to justly represent the stories of similarly oppressed and marginalized groups, qualitative research hoping to understand disability is experiencing warranted criticism because of *who* is doing (or is allowed to do) the research (Arzubiaga et. al., 2008; Barnes, 1996; Branfield, 1998; Heshusius, 2004; Shakespeare, 1996; 2006; Stinson, 1994; Stone & Priestly, 1996). Higher education is, by nature, an institution

founded on and buttressed by gate-keeping, often only accessible to those who benefit from systems of unearned economic, national, racial or ethnic, linguistic, gender or ability privilege, producing a largely homogenous population of doctoral candidates and faculty members. Thus, current and future Disability Studies projects must contend with this question and interrogate researcher positionality, particularly with regards to people without disability identities doing this work. Scholarship about who can and should be doing the work of Disability Studies is as diverse and polarized as the challenges with which the field must contend. Noting the inevitable power differentials that persist, Branfield (1998) asserts that "no matter how 'sincere,' 'sympathetic' or whatever," non-disabled people are forever in positions of privilege and "all that this carries with it—domination, oppression and appropriation" (p. 143). Stone & Priestley (1996) highlight the "oppressive theoretical paradigms" and "oppressive set of social relations" in which much research on disability has taken place, characterized by "tragedy, impaired body and Otherness," and isolate *how* research is done (that is, the methodology employed) as the place to intervene, to begin to "[fight] the social oppression of disabled people" (p. 700). Shakespeare (2006) attempts to bridge the gap between abled and disabled and notes that most non-disabled people doing this work have very close connections to the disability experience through family members, colleagues, friends, etc. and thus "have a stake in solving the disability problem" (p. 197).

Davis (2000) proposes that due to their unique training and social location, there is a role for non-disabled academics (in this case, ethnographers) doing disability research where, "their expertise lies in their ability to produce writing which counters hegemonic discourses and their capacity to represent the complexity of people's lives through recognizing the importance of individual experience, culture and structure" (p. 203). Erevelles (2014) highlights the relative

messiness in doing research about disability while not claiming a disability identity, and poses an important set of questions for said researchers: **"**What is my relationship to disability? With what authority can I speak about disability? And why? Am I speaking with disabled people or about them? How does the validation of certain forms of speech/language that I adhere to include some and exclude others?" (Erevelles, 2014, Belonging/Borderlands section, para. 2). As Disability Studies research attempts to "define the boundaries between who should be in and who should be out" (Linton, 1998; Samuels, 2003 as cited in Erevelles, 2014) interrogation of where these boundaries fall, and who draws them, is particularly salient to this study. As Anzaldua (1983) confesses when reflecting on her own, at times, exclusionary word choices, "I too am seduced by academic language, its theoretical babble insinuates itself into my speech and is hard to weed out" (p. xxiv). The academic conventions of producing knowledge and scholarship in such relatively narrow ways and disseminated through narrowly-defined channels (who reads education journals other than academics?) butts up against the philosophical underpinnings that scaffold it in ironic, often hypocritical ways. Even as I write this, the image that keeps popping into my head is an American Sign Language idiom that, in the right context, can mean "hypocrite." This sign is produced by holding up four fingers on your dominant hand and, palm facing inward, moving them from one side of your mouth to the other. An English translation would be something like "Eat your words." Yet most of us press on, not yet brave enough to completely topple the institutions into which we're trying to gain credentials for membership, but hoping that by keeping a methodological journal and including positionality statements, it will be sufficient for now, vowing that "When I'm finished with my PhD, then I'll really do it differently." And so, I also kept a methodological journal and included this positionality statement, and tried to propose new ways of doing authentically participatory research with

individuals with intellectual and developmental disability labels. In this attempt, I hope to honor Leslie Feinberg, and continually test theory "against reality" because "theory that strays too far from experience becomes abstract—an idealist argument about how many angels can dance on the head of a pin" (Feinberg, 1998, p. 115.) As I detail throughout this dissertation, I was very often pulled between what I eventually came to understand as a false dichotomy between "theory" and "reality," finding it difficult to locate my findings, my participants and myself in less-than-absolute ways. Though I bristle at what I assume is Shakespeare's slightly ironic use of the phrase "disability problem," as the partner of someone who identifies as Deaf and disabled (also a member of "The Academy"), and friend of many disabled people, I understand my role as that of disabled-adjacent ally. A few years ago, my husband introduced me to a Deaf acquaintance of his who, in noticing that I signed, asked if I was also Deaf. My husband told her I was Hearing, but then used a Deaf cultural term to describe me that I still consider among the greatest compliments I've received: "No, but she has a Deaf heart." I like the poetry and ambiguity of that sentiment, and tried to remain mindful of it throughout this process.

Organization of this Dissertation

This dissertation is organized into seven chapters: 1) Introduction; 2) Literature Review; 3) Methods and Procedures; 4) Content Findings and 5) Methodological Findings; 6) Discussion; and, (7) Conclusion. Chapter 1 introduced how I arrived at my research questions, how I understand the "problem" at hand, and from which theoretical frameworks I drew to guide this study. It also reviewed terminology used throughout this dissertation and discussed my positionality as a researcher. Chapter 2 reviews relevant literature about postsecondary education and disability as well as qualitative methodology and disability, specifically intellectual disability. Chapter 3 describes the adapted Participatory Action Research (PAR) methodology

implemented via focus groups with visual supports that I employed to collect data. It also discusses my phenomenological approach to analysis, chunking and then coding the data to develop themes and present findings. Chapters 4 and 5 present and explore the themes that emerged from the data analysis and put them in conversation with extant scholarship. Chapter 6 will delve deeper into these findings and discuss how Disability Studies makes meaning of them. Finally, Chapter 7 will attempt to draw larger conclusions about what this study teaches us about inclusive postsecondary education practice as well as research with participants with intellectual and developmental disabilities while proposing new directions for future research.

Chapter 2

Literature Review

This study is organized around the following research questions: 1) How do students with intellectual and developmental disability labels describe and represent their college experiences? 2) What does inquiring into the experiences of college students with IDD labels teach us about inclusive postsecondary education? And, 3) What does inquiring into the experiences of college students with IDD labels teach us about doing research with individuals with IDD labels? As an inquiry rooted in and guided by the theoretical and methodological frameworks of Disability Studies, feminist theory and practice, and phenomenology, I utilize these vantage points as locations from which to better understand inclusive postsecondary education for SWIDD labels. In this section I review various bodies of literature and trace where gaps emerge and intersections converge to inform this dissertation. This review is organized into the following sections and includes corresponding sub-sections: 1) Intellectual disability: Origin stories; 2) The current context of postsecondary education for students with intellectual and developmental disability labels; 3) Qualitative research and individuals with IDD labels; and 4) Experiences of SWIDD labels in postsecondary education.

Intellectual Disability: Origin Stories

People with intellectual disabilities in the United States have endured long, complex histories characterized by neglect, abuse, marginalization and oppression. Though at the time done in the name of care, protection, and pity, they have been the recipients of some of the most egregious human and civil rights violations in our country's history, viewed through deficit-based lenses that denied them access to education, employment, community living, reciprocal social relationships and the corresponding benefits of full personhood (Biklen & Duchan, 1994;

Bogdan & Taylor, 1992; Trent, 1994). Believers in the principles of eugenics, from the Greek for "true genes," propagated ideas and practices that served to keep people with intellectual disabilities out of sight, counseling parents to place their children with such labels in institutions or "state hospitals" (Bogdan & Taylor, 1992; Carey, 2009; Trent, 1994). Along with dominant cultural narratives that blamed parents for their children's disabilities, lack of access to formal education and community supports left families with few options (Carey, 2009). Fear and pity-based messaging from the medical community told families that the best thing they could do for their disabled children was to send them to "state schools" where they would receive proper care, specialized education and therapeutic services (McGuire, 2016). In practice, institutions housed other genetic "undesirables," becoming de facto dumping grounds for not only people with intellectual and developmental disabilities but also for individuals viewed as delinquent: people who were poor, unwed mothers, LGBTQ individuals, and criminals (Carey, 2009; Carlson, 2001; Desjardins, 2012; Trent, 1994). The court systems were tools of segregation and, in many cases, sterilization, for many people deemed "Other," including people with disabilities (Carey, 2009; Desjardins, 2012; Trent, 1994). For example, in the 1927 Supreme Court case *Buck vs. Bell*, Carrie Buck, an unwed mother with an intellectual disability, was forcibly sterilized because, as Chief Justice Oliver Wendell Holmes ruled:

> It is better for all the world, if instead of waiting to execute the degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit for continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting Fallopian tubes…Three generations of imbeciles are enough" (as cited in Trent 1994, p. 198-9).

It wasn't until the 1970s that people with intellectual and developmental disabilities

began to move out of institutions and into schools. Thanks to sustained advocacy work of parents and some educators, the 1975 Education for All Handicapped Children Act (Public Law 94-142) guaranteed children with all disability labels access to a free, appropriate public education in the least restrictive environment. Prior to P.L. 94-142, only about one in five students with disabilities was educated in public schools, and this rarely, if ever, included students with more significant disability labels (Brown et. al, 1983). Though the law granted such students equitable access to public schooling in terms of physical presence, students with IDD labels did not often enjoy equitable access to or participation in the general education curriculum (Cosier, Causton-Theoharis & Theoharis, 2013). Even today, students with intellectual disabilities spend the majority of their days in segregated special education settings where they learn functional, life skills curricula and have few opportunities to develop reciprocal social relationships with peers without disabilities (Kurth, Morningstar & Kozleski, 2014). Although the law is on the side of inclusion, on average, only 16% of students with IDD labels spend 80% or more of their days in general education settings (U.S. Department of Education, 2014). These placement trends vary by state, ranging from 4.4% of students with IDD labels educated in inclusive settings in Washington and 4.8% in New Jersey, to 64% in Iowa and 45.5% in Alabama (U.S. Department of Education, 2014).

However, there is a steadily-growing literature base that reports more positive post-school outcomes for students with even the most significant disability labels who are educated in inclusive settings. Almost a half-century of research demonstrates that students with disabilities, even intellectual disabilities, who are educated in inclusive settings make greater academic and social gains, report higher levels of satisfaction and belonging, and go on to participate in some kind of postsecondary education in higher numbers (Blackorby, Chorost, Garza, & Guzman,

2003; Cole, Waldron, & Majd, 2004; Jackson, Ryndack & Wehymeyer, 2008-2009; Jorgensen, McSheehan, & Sonnenmeier, 2007; McSheehan, Sonnenmeier, Jorgensen, & Turner, 2006; Sonnenmeier, McSheehan, & Jorgensen, 2005). As will be discussed further in the next section, attitudinal and legislative changes set the stage for the cultural shift we are currently experiencing: postsecondary education is increasingly becoming not only a possibility, but a reality for students with IDD labels.

The Current Context of Postsecondary Education for Students with Intellectual and Developmental Disability Labels

In the past decade, students with intellectual and developmental disability (SWIDD) labels in the United States have enjoyed greater access to participation in postsecondary education (PSE) settings (Hart, Grigal, Weir, 2010). This increased access is the product of a confluence of circumstances in which college participation has become a reality including: changing attitudes about intellectual disability and college "appropriateness," federal legislative support, and increased availability of alternative pathway programs for students who might otherwise not meet standard admissions requirements. Subsequently, PSE participation is on the rise, contributing to positive post-school outcomes for individuals with IDD labels. This section details the current context of students with intellectual and developmental disability labels in postsecondary education.

Proponents of PSE for SWIDD argue that it's part of a "natural progression" from inclusive educational experiences in primary and secondary settings where students have been participating alongside their typical peers in academic and social contexts (Hart, Grigal, Weir, 2010). In fact, the reauthorization of the Individuals with Disabilities Education Improvement Act (IDEIA, Public Law 108-446, 1990, 2004, 2015) now requires that students' Individualized

Education Program (IEP) teams document and work towards goals that may include some kind of postsecondary education (Hafner 2008; Stodden & Whelley, 2004). Often beginning at age 14 (though a specific age is not mandated within the legislation), students' IEP teams engage in the process of "transition planning," to develop and implement educational goals, supports and services to inform their lives beyond high school (Kohler & Field, 2003; Lehmann, Bassett, & Sands, 1999). Though critics have rightly argued that many transition plans for students with IDD labels had at one time focused only on independent living skills or purely vocational training opportunities (Causton-Theoharis, Ashby, & DeClouette, 2009; Mallory, 1995), recent legislative changes suggest promising trends.

The Higher Education Opportunity Act of 2008 (HEOA, PL 110-315) includes important provisions for students with IDD labels in accessing postsecondary education opportunities including: first-time eligibility for federal student financial aid, establishing or expanding model demonstration programs as best practice examples of successful postsecondary programs, and establishing a national coordinating center to deliver technical assistance and evaluate postsecondary programs for students with IDD labels (National Coordinating Center Accreditation Workgroup, 2016). As noted by the National Coordinating Center Accreditation Workgroup in their recent report to Congress, these provisions have contributed to more inclusive course access for students with IDD and thus, "substantially better outcomes employment, social engagement, and community living" (Butler, Sheppard-Jones, Whaley, Harrison, & Osness, 2016; Grigal, Hart, Smith, Domin, Sulewski, & Weir, 2016; Hart, 2014; Moore & Schelling, 2015, as cited in National Coordinating Center Accreditation Workgroup, 2016, p. 13).

Participation of Students with IDD Labels in PSE

In the largest longitudinal study of students with disabilities representing data from over 11,000 participants, The National Longitudinal Transition Study-2 (NLTS2), found that only about one-quarter of students with IDD labels (about 28.7%) participate in some kind of postsecondary education (the lowest in any disability category), though it's unclear from these data what constitutes postsecondary education (Chiang et al., 2012; Newman, Wagner, Cameto, & Knokey, 2009; Newman et al., 2011; Sanford, et al., 2011). Particularly for students with IDD labels, opportuntiies for additional education or training after exiting high school could vary in rigor and quality, from vocational training, apprenticeship programs, alternative pathway programs or 2 and 4 year institutions. These numbers have increased steadily in the last decade and, due in part to the 2008 reauthorization of the Higher Education Opportunity Act (HEOA) noted above, are expected to continue to rise (Sanford, et al., 2011). In keeping with participation trends (or perhaps facilitating these participation trends), the number of postsecondary education programs for students with IDD have risen dramatically in the last twenty years (Grigal, Hart & Weir, 2014). The HEOA (2008) supported the development and implementation of inclusive postsecondary programs for students with IDD, and allows students to access these opportunities via "alternative pathways" other than meeting the institution's entrance requirements (Grigal et al., 2012; Grigal, Hart, & Migliore, 2011; Hart et. al, 2010; Thomas, et. al, 2012). The three types of alternative pathways via which students with IDD access postsecondary education are: 1) Dual or concurrent enrollment for high school students, 2) College-initiated programs and services designed specifically for adults with ASD and IDD, and, 3) Individual or family-initiated supports (Hart et. al, 2010; Hart & Grigal, 2009; Hart, Grigal, Sax, Martinez, & Will, 2006). When taken together, Hart and Grigal (2009) note that the three alternative pathways to

PSE for students with IDD comprise over 250[2] programs across the United States. However, of these currently available programs, it's unclear how many would be considered "inclusive," and, as-of-yet unclear how to define what an inclusive college experience comprises.

Outcomes for SWIDD Labels Who Participate in PSE

For individuals with disabilities (other than IDD labels), participation in postsecondary education opportunities contributes to many positive post-PSE outcomes including employment, social participation, independence, self-determination and overall quality of living (Causton-Theoharis, Ashby, & DeClouette, 2009; Hart, Grigal, & Weir, 2010; Lindstrom, Doren, & Miesch, 2011; Papay & Bambara, 2011; Stodden & Mruzek, 2010; Stodden & Whelley, 2004; Thoma et al., 2012; Thoma et al., 2011; Zafft, Hart, & Zimbrich, 2004). Individuals *with* IDD labels who access postsecondary education opportunities experience similar benefits including higher levels of academic achievement and social competence (Uditsky & Hughson, 2006), increased likelihood of obtaining paid employment with fewer on-the-job supports, and reported higher earnings (Migliore et al., 2009; Zafft et al., 2004). However, rich data of post-PSE outcomes for students with IDD is scant, focusing instead on how the presence of students with IDD labels affect their home institutions, the perceptions of their non-disabled peers, or their instructors (May, 2012; Westling et. al, 2013). Grigal et. al. (2014) notes that "…the most critical questions have yet to be asked or answered. What effect does a college education, in its many iterations, have on...people with intellectual disability?" (p. 289). McEathron and Beuhring (2011) note that because of the extreme heterogeneity of this body of literature, there exists a "fundamental barrier in understanding the effects of PSE" for students with IDD (McEathron &

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[2] Currently, Think College reports there are 269 alternative pathway programs across the U.S. for students with intellectual and developmental disabilities (See: https://thinkcollege.net/college-search).

Beuhring, 2011, p. 4.)

Inclusive PSE Programs for SWIDD Labels

In a 2009 *Think College* survey seeking to investigate the range of existing services for students with intellectual disabilities in what are billed as "inclusive" postsecondary education programs, significant variation was found specifically in areas of student participation, and access to and participation in typical courses (Hart et. al, 2010). Of the 149 survey respondents representing PSE programs across 37 states, most programs (75%) reported that they offered other instruction or social events specifically for students with IDD, and that students with IDD participated in instruction or social events only with other students with IDD (Hart et. al, 2010). Additionally, only about half of the respondents reported that students with IDD accessed their courses via the typical registration process, or received services from the college or university's office of disability services (Hart et. al, 2010). An even smaller percentage of programs (39%) reported offering residential components for students with IDD but again, within this 39% are campuses that serve one or two students or one-week summer "college experience" programs (Hart et. al, 2010). Currently there are only a handful of multi-year postsecondary programs for students with IDD that also offer on-campus housing options (Think College, 2019). These data call into question the level of "inclusiveness" of the programs represented, and highlight the need for research into the lived experiences of students with IDD who do access these programs. Likewise, in a policy research brief from the Institute on Community Integration at University of Minnesota, their review of existing PSE literature found additional inconsistencies with regards to: characteristics of enrolled students (how the programs themselves are defining "IDD"), characteristics of postsecondary institutions (2 year, 4 year, and the variability of available programs of study, social opportunities and other contextual factors), and student outcomes

(what outcomes were tracked and how, and varying definitions of student "success") (McEathron & Beuhring, 2011). Though *Think College* has developed a document that details the standards, quality indicators, and benchmarks for inclusive postsecondary education programs for students with IDD (Grigal, Hart, & Weir, 2011), there is little focus on student voices, perspectives or experiences other than a passing mention of "student satisfaction data" as one component of the "Ongoing Evaluation" standard (p. 4).

Despite this limited and heterogeneous literature base, there are a few promising practices that researchers have identified in developing and implementing successful inclusive PSE programs, along with supports and services for students with IDD labels. Hart et. al. (2010) summarized these promising practices as follows: instruction in natural environments, person-centered planning, local, regional and/or state level cross-agency coordinating teams, universal design, mentoring, educational coaching, engagement in competitive employment, social pragmatics and communication skills, self-determination/self-advocacy, and evaluation activities.

Authorized by the HEOA of 2008, Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSIDs) were established to "create or expand model programs at institutions of higher education or consortia" (National Coordinating Center Accreditation Workgroup, 2016, p. 17). Grantees who were awarded a portion of the $10.5 million of federal funding during the initial round (FY2010-FY2015) and $9.8 million in the second round (FY2015-FY2020) were given preference due to their commitment to implementing all or some of the promising practices noted above (20 U.S.C. §1140g(c). The research site selected for this dissertation project is part of the second cohort of TPSIDs that, along with 24 other model programs throughout the country, was awarded a portion of this second round of federal funding.

Evaluation data collected from the first TPSID cohort (2010-2015) report the following:

- 2,245 students attended programs at 52 campuses implementing 27 model demonstration grants

- Students enrolled in over 10,000 inclusive courses

- Overall, 45% of all course enrollments across the 5 years of data collection were in inclusive classes

- 846 students worked in a paid job while also attending the program

- Over 1,000 students earned a credential upon exiting (Grigal, Hart, Smith, Domin, & Weir, 2016) (National Coordinating Center Accreditation Workgroup, 2016, p. 18).

Though TPSIDs are all required to conduct internal evaluation activities and may use student interviews or surveys as part of these activities, it's unclear how significant of a component student experiences are, or how those experiences are garnered. Additionally, as noted above, the *Think College* Quality Standards allude to "collection of student satisfaction data" as one component under Quality Indicator 8.1 within Standard 8 "Ongoing Evaluation," but again, this concept is not operationalized (Grigal, Hart, & Weir, 2011, p. 4). As many leaders in this field have championed the need for an agreed-upon "taxonomy" that defines what an inclusive PSE program for students with IDD really *is*, the *Think College* National Coordinating Center Workgroup recently released a report to Congress detailing their recommended model accreditation standards. The purpose of establishing these standards is to:

> …Provide guidelines for colleges and universities on how to develop and improve programs, validate these programs within institutions of higher education, and give students and their families an assurance of quality. Accreditation standards will move the field forward on the path to real opportunities for students with ID to experience higher

education resulting in competitive integrated employment and community living (National Coordinating Center Accreditation Workgroup, 2016, p. 3).

The Workgroup's Model Accreditation Standards are divided into the following categories: Mission, Student Achievement, Curriculum, Faculty, Facility, Equipment and Supply, and Administrative and Fiscal Capacity, and paint a picture of what the ideal postsecondary education experience looks like for students with IDD. It seems a striking omission not to consider how the voices of students who actually attend these model programs could be solicited to better inform what makes them successful, or what they could improve. Though student experiences or levels of satisfaction are admittedly difficult to measure, for a population as historically disenfranchised as individuals with intellectual disabilities, it's puzzling as to why student voices are not more fully integrated into assessing current programs or envisioning future ones.

The next section will review the challenges as well as best practices of qualitative research methods seeking to investigate and represent the experiences of people with intellectual and developmental disabilities.

Qualitative Research and People with Intellectual Disability Labels

The relationship between the disability community and research community boasts a history characterized by abuse, oppression and ultimately distrust (Abberley, 1992; Oliver, 1990, 1992; Morris, 1992; Rioux & Bach, 1994). Much of the scholarship "about" disability has been criticized as a misguided effort to "help" or "cure" disabled people, motivated by fear, pity and assumptions based in deficit models of what it means to experience disability and yet, doesn't actually consult disabled people or include them in the research process (Charlton, 2006; Oliver 1992; Petersen 2011; Shapiro, 1993). In the realm of qualitative research, scholars note the

tradition of stories being told *about* people with disabilities, privileging the voices of parents or professionals, as opposed to people with disabilities themselves (Ashby, 2011; Biklen, 1988; Biklen & Duchan, 1994; Blatt, 1981; Bogdan & Taylor, 1976, 1994; Kliewer & Biklen, 1996). Even in qualitative research seeking to address the lives of individuals with labels of "severe" or "more significant" disabilities (such as people with IDD labels) data is gleaned not from the people themselves but from their parents and other family members, caregivers, teachers or other support professionals (Ashby 2011; Carlsson, Paterson, Scott-Findlay, Ehnfors & Ehrenberg, 2007; Lloyd, Gatherer & Kalsey, 2006; Wintle, 2012). Disabled participants "become the objects of research, where their voices are mediated and interpreted" (Ashby 2011, Problematizing Voice and Method section, para. 4).

Thus, in order to realize the vision of the disability rights movement and put in practice the rallying cry of "nothing about us without us" (Charlton, 1998), qualitative researchers are tasked with facilitating scholarship that privileges disabled people as experts worthy of consultation about their own lives (Charlton, 2006; Oliver 1992; Petersen 2011; Shapiro, 1993; Zarb, 1992). Though qualitative inquiry seeks to excavate larger meanings by engaging people with disabilities about "what *they* are experiencing, how *they* interpret their experiences, and how *they* themselves structure the social world in which they live" (original emphasis, Psathas, 1973, as cited in Bogdan & Biklen, 1992, p. 32), questions and tensions remain around for whom this research is intended to benefit, or who it actually does benefit in practice? What does it purport to do? Or, as Petersen (2011) posits: is it practically "useful" and accessible for participants? (Barton, 2006, 2005; Oliver, 1992; as cited in Petersen, 2011). And, most salient for this study: if "telling one's story" is the means via which the world can better understand the diverse experiences of people with disabilities as they enjoy greater access to postsecondary

education spaces, what are ways of "telling" that do not rely *only* on one's ability to talk about themselves and their experiences?

Challenges of Qualitative Research and Individuals with IDD Labels

Though qualitative approaches to describing complex phenomena such as the postsecondary education experiences of students with intellectual and developmental disability labels are well-suited to negotiate the inevitable gray areas (that is, these experiences are not easily "measured"), they are not without challenges. Such foundational components of qualitative research such as garnering informed consent, communication and voice, and interviewing carry with them a set of ableist philosophies and practices that need to be negotiated to design and implement socially just qualitative research projects. Detailed below are several of these challenges and limitations identified in the literature about doing research with this unique population.

Informed consent. In a comprehensive review of qualitative research with individuals with disabilities, Nind (2008) details the challenges experienced by researchers at each stage of the research process from design, ethics, data collection, analysis and reporting. She focuses her review on studies conducted with both children and adults with what she terms "learning difficulties, communication difficulties or other disabilities such as autism with associated complex challenges in communicating, understanding or taking part in research" (p. 3). Though primarily focusing on research conducted in the United Kingdom, the studies reviewed in Nind's (2008) paper have implications for this discussion as well. Scott et. al. (2006) delineates the three primary considerations in establishing a participant's ability to give consent: the person's competence as defined by traditional intelligence metrics such as IQ tests, his/her/their ability to make autonomous, informed decisions, if the proposed study is in the person's own best

interests, and the study's balance with public interest. Unsurprisingly, for participants with IDD labels, this set of requirements are accompanied by additional considerations that, depending on the researcher's epistemological standpoint, will affect the kind of study designed and implemented. For example, some researchers have attempted to measure an individual's ability to give informed consent by presenting him/her/them with a series of stories about medical interventions and then conducting an interview to establish comprehension of not only the interventions but the associated risks and benefits and the participant's ability to communicate their decision and rationale (see Arscott, Dagnan, & Stenfert Kroese, 1999; Jones & Stenfert Kroese, 2007). Alternatively, Harris (2003) points out that people with IDD labels often live in social realities where choices are fixed or even non-existent, or they may fear making the perceived "wrong decision" and disappointing their families or support stuff, thus emphasizing the importance of contextual factors in how someone negotiates decision-making. Due to the often deficit-based understanding of disability from researchers' respective Institutional Review Boards (IRB), participants with IDD labels fall into the category of "vulnerable populations," who, because of "cognitive or communicative vulnerability," may not be perceived as able to give consent (Lake & Wendland, 2018). However, IRB policies and procedures grew out of an ugly, abusive history of research being done on individuals with IDD labels, and so these protections remain in place to guard against future abuse (Blake, 2007). Thus, it's important to note that although researchers' individual epistemologies may align with Disability Studies philosophies, the reality of doing research with participants with IDD labels carries with it layers of ableism to negotiate (Gustafson & Brunger, 2014). Gustafson & Brunger (2014) note that "labeling the disability community as vulnerable assumes incorrectly that all members are similarly positioned and therefore disadvantaged, at risk, or in need of protection based on a

single category of dif- ference" (p. 1001). In fact, one of the institutional realities that contributed to my decision to abandon a Participatory Action Research (PAR) framework was this conflict between participants' role in study design and the IRB approval process (Lake & Wendland, 2018).

Communication and voice. A salient challenge for qualitative researchers is the struggle to access this ideal of the "authentic voice" of one's participants (Mazzei & Jackson, 2009). Ashby (2011) describes voice as "the right and the ability to make oneself heard and to have one's experiences and perspectives available to others; to participate in the construction of the self and to decide how to represent that self to others" (para. 3). Drawing on Fry (1977), Wickenden (2011) notes the connection between a person's ability to talk and his or her perceived level of humanness or personhood—one's voice is a "window into their mind" (Wickenden, 2011, Voice section, para. 1). Additionally, scholars across disciplines have noted the persistent and oftentimes detrimental link between eloquence and perceived intelligence. Judgments about competence are inextricably linked to one's ability to express themselves via speech. For individuals whose competence is questioned at the outset, the "truth" or value of their "voices" have been persistently dismissed or discredited (Ashby, 2011; Biklen, 1992; Biklen & Burke, 2006; Ferri, 2006; Kliewer, 1998).

Thus, qualitative research, according to Mazzei and Jackson (2009), aims to "privilege this voice, to 'free' the authentic voice from whatever restrains it from coming into being, from relating the truth about the self " (p. 1). Take, for example, a semi-structured interview that follows the predictable format of alternating between researcher question and participant answer: the entire communicative encounter is presumed to be spoken. As a central component of qualitative research, the "interview" is accompanied by assumptions of verbal interaction or, as

Carlsson et. al. (2007) notes, "a speech event" (p. 1362). Additionally, qualitative research texts instruct students to record real-time field notes that might include facial expressions or body language, and audio recordings are transcribed into written form, endeavoring to capture the intricacies of verbal speech—the *umms, ahhhs* and potentially meaningful pauses that, when taken together, create a written record of a verbal and auditory exchange (Bogdan & Biklen, 2007; Spradley, 1979). The taken-for-granted assumption is, of course, that the researcher and the participant receive information aurally and express information verbally and facial expressions have consistent meaning across individuals.

Clarke et. al. (2005) interviewed 27 people with "learning difficulties" and corroborated Booth and Booth's (1996) "four areas of challenge" with the interview process itself: "inarticulateness (linked to low self-esteem, isolation and anxiety as well as language skill levels); unresponsiveness in open questioning; difficulty in generalizing from experience and thinking in abstract terms; and, conceptual difficulty around time, making it difficult for them to tell their story." (as cited in Nind, 2008, p. 10). Beail and Williams (2014) suggest that due to participants' limited verbal and cognitive abilities, unstructured interviews with individuals with intellectual disabilities may be shorter in length and potentially less "rich." Conversely, Lewis (2004) discovered that for participants with IDD labels, semi-structured interviews with more traditional question and answer approaches were more difficult than open-ended, participant-directed narratives. Confirming introductory qualitative research principles that the answer given often depends on how the question is phrased (Beail & Williams, 2014; McVilly et. al. 2008), this challenge has been characterized as even more significant when considering participants who do not utilize verbal speech as their primary mode of expressive communication. A number of scholars (Ashby, 2010; Biklen, 2005; Broderick & Kasa-Hendrickson, 2006; Cowley, 2012;

Groove, 1999; Petersen, 2011; Wickenden, 2011) discuss augmentative and alternative communication (AAC) users as an example, cautioning that the data generated from such participants should be further scrutinized because, as Light and Binger (1998) note, a "third person" may, however unintentionally, be limiting the vocabulary from which the participant can respond (e.g. If an AAC device has a certain number of boards or screens with a fixed number of picture-supported words or icons, rather than a full QWERTY keyboard, someone can only respond in so many ways). Tensions inevitably surface when the dominant communication paradigm is disrupted and researchers or participants utilize alternative modes of receptive or expressive language and, perhaps due to several mediating factors such as the presence of interpreters, support staff, or various technologies, questions of authenticity or even authorship arise (Ashby & Causton-Theoharis, 2009; Ashby, 2011; Wickenden, 2011; Woodfield, 2016.)

Authorship and validity. Though there exists a large corpus of literature from feminist theory and critical race theory about not only what counts as knowledge or "whose knowledge counts," the continual evolution of Disability Studies and increased participation of persons with intellectual and developmental disabilities in postsecondary educational settings (however small in its current iteration) raises new epistemological considerations, namely: If people with intellectual and developmental disability labels are largely read as incapable of producing "academic" or "scholarly" knowledge, how then are their contributions to qualitative research assessed or valued? Likewise, it raises new methodological considerations about whose voices "count," and, depending on how those voices manifest, are they to be believed?

Many scholars persist in collecting multiple sources of qualitative data when investigating the postsecondary education experiences of individuals with intellectual disabilities (Casale-Giannola & Kamens, 2006; Hamill, 2003; O'Brien, et. al, 2011; Paiewonsky, 2011;

Redd, 2004). Redd (2004) discusses her rationale for selecting a multiple method case study (as

opposed to a single method case study) as the methodological approach to researching the

experiences of individuals with IDD labels in postsecondary education noting the "potential for

misunderstandings" and "concern with participant acquiescence" as threats to her study's

validity (p. 95). Though it's also in accordance with best practices in qualitative research (and all

research) to triangulate data to protect against interpreting a phenomenon from one angle only

(Potter & Wetherell, 1987) it's significant that, when reporting findings from other studies that

isolate the attitudes or experiences of individuals *without* disabilities, those data are not always

triangulated. For example, Griffin et. al. (2012) and Westling et. al. (2013) investigated the

attitudes of typical college students about individuals with IDD labels participating in an

inclusive program at their same institutions. In both studies, the authors administered one survey

to typical students living on the selected campus, and reported data from respondents. Though no

study is without limitations, these data from survey responses of typically-enrolled college

students were inherently trusted, and not triangulated. Additionally, in other qualitative studies

investigating attitudes and perceptions of typical students or attitudes of instructors with regards

to students with IDD labels, researchers utilized one data collection approach (in these cases,

interviews) in service of their research questions (Ashby, Causton-Theoharis & DeClouette,

2009; Carroll, Petroff & Blumberg, 2009). Cowley (2013) suggests that, "the unfortunate

assumption is made that students labeled with intellectual disabilities do not have the insight to

share their stories or the capacity to reflect on their lives" and proposes that, "…we as

researchers must look to the systems that have been put in place that limit the opportunities for

these young adults to ever share their stories" (Cowley, 2013, p. 56). Building on Cooney (2002)

and Smith and Routel (2010), Cowley (2013) reframes potential difficulties with interviewing

experienced by individuals with IDD labels not as related to deficiency but (as with arguments in support of reframing educational outcomes) but related to access. She notes that, "lack of opportunities many young women with disabilities have had in sharing what is important about their education with professionals or in directing their educational paths (Cooney, 2002; Smith & Routel, 2010) and dominant constructions of competency," might better explain what happens in the interview encounter (p. 58). Cowley (2013) adds that because of this, "…it was important for me to come to the interview prepared with various probes ("give me an example," "take me through _____," or "what did you say then?") in addition to the aforementioned interview guide" (p. 58). Erevelles (2005) ponders about the ability of "people who have been identified as cognitively disabled, competent (or incompetent) to represent themselves? Is it possible that these people can have observable physiological, cognitive, or behavioral disabilities, but also exhibit behavior and thinking that could be termed "normal" — that is rational?" (Erevelles, 2005, p. 4). Thus, not only do individuals with IDD labels disrupt the paradigm of "college student," they also disrupt qualitative inquiry's deeply-entrenched (though increasingly questioned, see: Fontana & Frey, 2005) belief in the testimony of its informants, challenging researchers to interrogate their own assumptions about autonomy and authorship within the research encounter.

Even though qualitative research methodologies are not uncomplicated tools with which to investigate the experiences of individuals with intellectual and developmental disability labels, scholars have reported key promising practices that various qualitative traditions boast. Due in part to shifts in thinking about disability as socially-constructed rather than medically-determined, qualitative researchers' increased emphasis on the experiences of individuals with disabilities has, as Nind (2014) notes, logically evolved to seeking out those experiences via their

own voices. Therefore, the next section will review the potential of qualitative methods that are also inclusive and participatory, to garner rich data and (ideally) foster positive experiences with participants with IDD labels.

Postsecondary Education Experiences of Students with Intellectual and Developmental Disability Labels: Alternative Pathways Necessitating Alternative Methodologies

As more colleges and universities open their doors to students with IDD labels, the body of literature about those programs and institutions logically grows. However, much of the data collected and reported is program evaluation data that may include components of student experiences, perceptions and attitudes, while not being the primary focal points of the evaluation. In a review of the literature to date, Thoma, et. al. (2011) noted that most data collected was regarding program design, implementation, and corresponding supports and services, but that student outcome data are not often reported, nor are they attempted to be collected. In a comprehensive overview of postsecondary education options for individuals with Autism Spectrum Disorder and intellectual disabilities, Hart, Grigal and Weir (2010) present information on each part of the process for students accessing PSE including the historical and philosophical rationale, different models of participation and implementation, best practices in supports and services, and recommendations for future research. In proposing how PSE institutions can approach evaluating their programs (since, as they note, there is not an evaluation tool commercially available for this unique population of students), the authors suggest several potential data sources to include in developing an evaluation plan. These data sources include reports of student support staff, student goal-setting and progress reports, satisfaction surveys of multiple stakeholders, results of overall quality of life measures or measures of self-determination and autonomy, exit data, and garnering post-school outcomes (Hart, Grigal &

Weir, 2010). The authors' proposed evaluation tool focuses on the program, rather than the students. Additionally, their recommended future research agenda in this burgeoning field, though exhaustive, does not include an item to get at the experiences of the students themselves.

Of the paucity of studies that do explicitly investigate the PSE experiences of students with IDD themselves, the methodologies employed and findings reported vary significantly. In their case study, Page and Chadsey-Rusch (1995) found that two young men with intellectual disability labels (at the time of the study, they were described as "mentally retarded") felt more independent and more "grown-up" after taking community college courses, while Hamill (2003) found that a female student with an ID label had difficulty developing reciprocal social relationships while auditing courses at a four-year college. Neubert and Redd (2008) built on findings from Redd's 2004 dissertation, a case study of a transition program at a community college for students with intellectual disabilities. Student experiences were one component of this study, conducted via focus groups with other participants with ID. Neubert and Redd (2008) found similar themes as the studies reviewed above, noting that some students used the term "freedom" to describe what college meant to them. Alternatively, other students described being treated "like babies," expressing frustration that they were not able to fully participate in campus life (Neubert & Redd, 2008). Most striking about the Neubert and Redd (2008) study was how little student voices were woven throughout the larger narrative. Most findings reported were based on interviews with parents and PSE staff members and, in this study, were the perspectives most privileged in the service of their research questions.

Because of the aforementioned challenges of conducting research with individuals with IDD labels (Arscott, Dagnan, & Stenfert Kroese, 1999; Beail & Williams, 2014; Booth & Booth, 1996; Clarke, et. al, 2005; Harris, 2003; Jones & Stenfert Kroese, 2007; McVilly et. al, 2008;

Nind, 2008; Redd, 2004; Scott, 2006), there is a push for inclusive research methods that can more purposefully and authentically engage participants in the research process (deFur & Korineck, 2008; Fogg & Harrington, 2009; Neubert & Redd, 2008; Nind, 2014; Paiewonsky, 2011; Webb, Patterson, Syveurd, & Seabrooks-Blackmore, 2008). Several studies have offered suggestions on how to do this, highlighting the following: teaching participants about the research process (Valade, 2008; K. Ward & Trigler, 2001), using plain language (Heller et al., 1996), using multiple and intensive data collection strategies (Mactavish et al., 2000), presuming participants' credibility (Mactavish et al., 2000; Tregaskis & Goodley, 2005), developing easy-to-understand approaches to seek informed consent (Heller et al., 1996), and producing dissemination materials that are universally accessible and meaningful (Tarleton, 2005; Tierney, Curtis, & O'Brien, 2009; Walmsley & Johnson, 2003). However, as Paiewonsky (2011) notes:

> What is missing from the literature is any evidence that students with ID have the opportunity to critically evaluate their college experience with research methods that seek to gain a full understanding of how their expectations are or are not being met. Without this information, policy makers and practitioners will continue to develop postsecondary education initiatives for students with ID that may not meet their unique needs. Designing research methods with college students with ID that are accessible and meaningful to them has the potential to enable them to influence and even control research that is focused on their lives (p. 32).

Due in part to the reasons cited previously for why student voices are not more central in scholarly literature, Paiewonsky (2014) proposes that since students with IDD are afforded non-traditional pathways to access PSE experiences, the research methods employed to document those experiences should be "equally accessible, supported and non-traditional" (p. 1).

"Inclusive research" is a relatively new term in the scholarly community to describe projects seeking to design and conduct inquiries that are aligned with principles of social justice (Cook, 2012; Nind, 2014). Walmsley and Johnson (2003) state that for research to be considered "inclusive" of its participants it must "access and represent their views and experiences" (p. 16) and ultimately benefit the participants in some way. For inquiries to also claim "participatory" labels, Bourke (2009) specifies that participants must be involved in all stages of the process including study design, data collection and analysis and findings dissemination. However, scholars highlight that participatory research often exists on a continuum, with varying levels of consultation and engagement from participants (Greenwood, Whyte & Harkavy, 1993; Holland, Renold, Ross & Hillman, 2008; Kemmis & McTaggert, 2000; Nind, 2014; Oliver, 1997).

Participatory action research (PAR) is one qualitative research methodology that shows promise in working with individuals with IDD labels. Though there are only a few studies that investigate postsecondary education via PAR (O'Brien, 2009; Paeiwonsky, 2011; Prohn, 2014), this inherently flexible approach has proved useful in facilitating the voices of individuals with IDD to share their experiences about other subjects such as: their health (Jurkowski & Paul-Ward, 2008), participating in circles of support and how those circles support transition (Stevenson, 2007), issues surrounding transportation (Valade, 2008), social inclusion (Mactavish et al., 2000), self-advocacy (Garcia-Iriarte, Kramer, Kramer, & Hammel, 2009), and overall quality of living (Ward & Trigler, 2001). Emphasizing its cyclical nature, Kemmis and McTaggert (2000) note that PAR is comprised of sometimes multiple iterations of planning, implementation and reflection. Paiewonsky (2014) identified PAR as ideally suited to "get at" college experiences in that: "…students with intellectual disabilities are not just research subjects. They are invited to become co-researchers. This leads to richer results and to an

increased sense of contribution among students who take part in this work" (Paiewonsky, 2014, p. 1). Additionally, the guiding principle of PAR emphasizes a strong collaborative component in that, "you [the researcher] are not asking them [the students with ID] to participate in *your* study. You are asking them to research college *with* you, to share the results, to take action, and to reflect on the work together" (Paiewonsky, 2014, p. 2).

In her 2011 study, "Hitting the Reset Button on Education: Student Reports on Going to College," Paiewonsky (2011) employs PAR to garner the college experiences of students with ID who were part the Massachusetts Inclusive Concurrent Enrollment Initiative (ICE), a model that was implemented across the state in 2007. The program model included students from seven community colleges and 30 school districts and supported students to set career goals and then pursue inclusive college coursework to work towards those goals (Paeiwonsky, 2011). By implementing a PAR approach, Paeiwonsky's (2011) role was that of a "research facilitator," recruiting nine student researchers to collaborate with her in researching their own college experiences and making recommendations for improvements. Paeiwonsky (2011) utilized multiple data sources including her own field notes and photographs, audio recordings, and student narratives, student photos and student video clips. The student researchers proceeded through six phases of research activities over the course of two semesters, focusing their inquiries on areas of particular interest to them, with projects that sought to investigate support and accommodations, working with educational coaches, navigating social relationships, developing advocacy skills, self-discovery, resilience, and new feelings of freedom and independence. In accordance with the PAR process, the students documented their experiences, shared the resulting photos and videos, discussed data, made recommendations to relevant stakeholders, and reflected on the process. Themes included student insights about their new

college identities and expectations of them, participating in different classes, navigating transportation, working with educational coaches, and campus life more broadly (Paeiwonsky, 2011). Overall, the student researchers described college as "an opportunity to reinvent themselves as young adults who were part of an academic and social community," who were held to the (sometimes difficult to meet) high expectations commensurate with their non-disabled peers (Paeiwonsky, 2011, p. 39). By including students with IDD labels as co-researchers in the process of excavating and representing their own experiences, Paeiwonsky (2011) notes that "students can build an awareness of inquiry, reflection, and action in a direct and meaningful way" and "make suggestions to improve the college experience" to further "[shape] an inclusive college education" (p. 41). Chapter 3 will discuss how this study began with a PAR-informed design but, because of methodological changes made, evolved past claiming that label. Chapter 7 reflects on the realities of doing research that claims "participatory" aims, proposing new methodological questions to consider in future scholarship.

Often a complement to participatory methodologies, studies that utilize photography or other visual supports show promise in investigating and representing the college experiences of individuals with IDD labels. O'Brien et. al.'s (2009) study of students with ID at a university in Ireland utilizing a variety of methods and data sources including focus group interviews, student diaries, and a Photovoice exercise (Wang & Burrish, 1997), is one example of a study that includes student voices to describe student experiences. In this study, students take photos meant to illustrate the changing nature of their identities as college students and record diary entries as they proceed through the program. They also described perceptions of support staff, friendships and the development of their own self-advocacy in focus group interview settings (O'Brien et al., 2009). The students' "journeys," as O'Brien et. al. (2009) describes them, each progressed via

different "pathways," categorized as: "student as a learner; student as a class member; student as a friend; student as a worker; student as a different person" (O'Brien et. al., 2009, p. 288.) O'Brien et. al. (2009) concluded that students' college experiences "opened up a whole new way of being" for them, characterized by the hopes and fears of typical college students including increased self-esteem and confidence coupled with negotiating the uncertainty of what to do upon graduation (p. 291). Paiewonsky (2011) notes that O'Brien et. al.'s study (2009) was able to uncover findings "that demonstrated how college was affecting the lives of students with ID both academically and personally in ways traditional methods might overlook" (p. 32).

In his dissertation research investigating the social inclusion experiences of college students with intellectual disabilities, Prohn (2014) also utilized photographs as visual supports to elicit these experiences. Building on Wang & Burris (1997) and Wang (1999), Prohn (2014) trained student participants in basic photography skills and ethics and conducted individual Photovoice interviews with them to facilitate students' understanding and representation of their perceptions of social inclusion in college. In his findings, Prohn (2014) noted that students described their experiences with social inclusion in diverse ways that were produced from the three interacting variables of belonging, attributed worth, and context, thus defying a singular narrative. Additionally, he discovered that beyond only seeing themselves as "students," they conceptualized their roles as "employees, researchers, presenters, friends, advocates, and contributors," while also viewing themselves as "competent adults with the skills needed to build and maintain social networks" (p. 175-6). He concluded that the visual supports provided by the Photovoice method was a "user-friendly" and "effective vehicle for students to directly describe their social experiences and the degree to which they were included…Students told their stories and created identities for themselves that they wished to share" (p. 182-3).

Characteristics of Gaps in the Literature

This discussion has sought to review the existing literature about the experiences of students with intellectual and developmental labels in postsecondary education. As evidenced above, the gaps that exist in this steadily growing body of literature are: 1) Limited inclusion of student voices in research about student experiences; and 2) Limited consensus on what inclusive postsecondary education actually is. Though it's difficult to make sweeping generalizations from scholarship that requires "considerably greater consensus and consistency in how key program characteristics, activities, and outcomes are defined in practice" (McEathron & Beuhring, 2011, p. 4), alternative methodologies have revealed exciting possibilities for future research. Of the relatively scant body of literature that explicitly garners student experiences, findings demonstrate that, when given alternative, inclusive and participatory means via which to share their experiences, participation in postsecondary education opportunities allows students with IDD labels to reinvent themselves, discover new parts of their identities, take on roles previously unknown to them, and experience newfound freedoms (Ashby & Causton-Theoharis, 2009; O'Brien 2011; Paeiwonsky, 2011.) Thus, if college is "a place to broaden perspectives, consider new ideas, and envision a world as it could be," (Ashby & Causton-Theoharis, 2012, p. 277) then it's time to facilitate opportunities for college students with IDD labels to share their stories and experiences, have their voices represented in research, and reinvent what it means to be college students.

Devault & Gross (2007) remind us that the process of "representing others" is neither objective nor benign: "therefore, understanding how we represent others, who has the power to represent others, and the implications of our representations of others is imperative to any feminist research project" (p. 192). I would add, however, that this dissertation is also an

exercise in how, via what means of communication, with what supports, and under what conditions, people with IDD labels are able to represent themselves and their experiences in postsecondary education spaces. The stories of individuals with IDD labels in postsecondary education are not only valued for their message but for the telling itself (Ferguson et al., 1992). Particularly for individuals with intellectual and developmental disabilities, the idea of intelligence or competence as a "social construction" remains contentious. So contentious, that even disability scholars wrestle with this:

> The very epistemology of the minority group assumes that humans are agents in the social interpretation of their world, rather than as reactors to our confrontations with an unchanging world of facts that are 'out there' in the 'real world.' The challenge of profound retardation, however, is precisely how close it seems to come to the absence of agency…One reason for the almost total absence of qualitative research with profoundly retarded and multiply handicapped individuals is the difficult in conceiving the social world of someone whose experience of concepts and communications is so uncertain for us (Ferguson 1988, in Erevelles 2005, p. 70.)

Though the abovementioned passage originally appeared in a text almost 30 years ago, the sentiment remains true. The pervasive disbelief in the variously manifested voices of individuals with intellectual and developmental disabilities and the accompanying presumptions of incompetence continue to seep into the ivy-covered walls of institutions of higher education. It is within this climate that this research lives, and with which it had to contend. Thus, if the social worlds of individuals with IDD labels are difficult to conceive, as Ferguson (1998) notes, for "us," [people without intellectual disabilities] then perhaps "we" should relinquish the research reins to "them" and see where we can all go together?

This chapter reviewed extant literature about the history and context of postsecondary education for students with IDD labels. It began with an overview of intellectual disability broadly and noted changes in attitudes and policy that have facilitated college access for this unique population. Additionally, this chapter traced the gaps present in current scholarship with regards to documenting and representing what the postsecondary education experiences of students with IDD labels are, and suggest the possibilities of inclusive, participatory research methodologies to get at those experiences. The next chapter will discuss the methods and procedures employed in this dissertation project.

Chapter 3

Methods and Procedures

This chapter presents the methods and procedures I employed to address the following research questions: 1) How do students with intellectual and developmental disability (IDD) labels describe and represent their college experiences? 2) What does inquiring into the experiences of college students with IDD labels teach us about inclusive postsecondary education? And, 3) What does inquiring into the experiences of college students with IDD labels teach us about doing research with individuals with IDD labels? In the first section about methods, I briefly introduce how qualitative research methods have been utilized to investigate the experiences of individuals with intellectual disabilities broadly. Then, I discuss this dissertation's design: focus group discussions informed by Participatory Action Research (PAR) methods with visual supports. In the second section about procedures, I detail what happened throughout the data generation and analysis phases and how the study veered away from its initial PAR-informed design. This chapter concludes by introducing the remainder of the dissertation and summarizes the content of the subsequent chapters.

Methods

The purpose of this qualitative inquiry was to investigate the college experiences of students with intellectual and developmental disability (IDD) labels. To get at these experiences, ten students with IDD labels participated in weekly focus group meetings to share and discuss different aspects of college. Utilizing students' digital photographs as visual supports and conversation prompts, this study sought to employ a Participatory Action Research (PAR) approach to data collection and analysis in efforts to center student experiences and privilege

student voices. However, as in many qualitative projects, this study ended in a very different place from where it began, offering salient lesson learned about studies that claim a "PAR" designation.

The project of qualitative research broadly is to "better understand human behavior and experience" and attempt to "grasp the processes by which people construct meaning and describe what those meanings are" (Bogdan & Biklen, 1992, p. 49). For researchers who "study people who have been marginalized," such as individuals with disabilities, qualitative methods also "hope to empower their research informants… [by engaging] in dialogue with their informants about their analysis of observed and reported events and activities" (Bogdan & Biklen, 1992, p. 49). Classic qualitative studies that have sought to narrate the disability experience such as Goffman (1963), Scott (1969) and Groce (1985) have "proven their power to describe and clarify the interdependence of human interaction, cultural attitudes, institutional processes, and public policies" (O'Day & Killeen, 2002, p. 9). For researchers engaged in scholarship seeking to understand the lifeworlds of individuals with disabilities, qualitative methods have provided exciting, though not unproblematic tools with which to endow "speaking subjects with a special significance" (Atkinson, 2003, as cited in Ashby, 2011, Broadening the conceptualization of voice beyond verbal speech section, para. 1). However, unique challenges arise when the "telling" of one's story cannot be accomplished through traditional avenues. For individuals with IDD labels who may communicate via non-dominant means, or require various supports to access academic and social experiences, the project of qualitative researchers necessarily changes (Ashby, 2011). The *ability* to "articulate ideas…is [often] viewed as more important than the actual message itself" (The Effects of a Medium section, Brunson & Loeb, 2011, para. 1), centering methodological concerns about how research can fulfill its participatory aims to

"meaningfully include people with learning difficulties as co-researchers" (Goodley, 2004, p. 50). Thus, as qualitative scholarship seeks to grapple with new and increasingly nuanced questions, new and increasingly nuanced methods are necessary to fulfill the promise of equity and justice for this historically silenced population and "identify a new methodology commensurate with fighting the social oppression of disabled people" (Stone & Priestly, 1996, p. 699). By employing a focus group-based approach to data collection informed by Participatory Action Research (PAR) methods with visual supports, my hope was to understand the increasingly common phenomenon of students with IDD labels participating in college and reframe the paradigm about how to do research with participants with IDD labels.

Design

The purpose of this study was to understand how students with intellectual and developmental disability (IDD) labels describe and represent their college experiences. Most of the students who participated in this study had participated in a seminar-style group the previous academic semester. In that group, they worked on developing and documenting their own personal narratives and so this study served as an extension of the work in which they were already engaged. Inspired by the PAR structure of Paeiwonsky (2011), data generation occurred simultaneously on both the student and researcher levels. To support their focus group discussions, students shared selected digital photographs, organized around co-generated topics relevant to college life such as: academics and friendships. I facilitated the group discussions, took field notes, and wrote research memos directly after each session. This study generated approximately fifteen hours of audio recordings that I transcribed into over 300 pages of data. Additionally, I conducted participant observations outside our focus group sessions, attending social events including: a local hockey game, a team-building day at the university's ropes

course, the program's end-of-the-year celebration, and numerous informal student gatherings at the research site. The participant observations painted a fuller picture of the students in this study, but the primary sources of data from which this work draws are the focus group transcripts. In Chapter 7 I discuss what might have been gained or lost from relying primarily on the focus groups to draw conclusions.

As noted in the previous chapter, the theoretical frameworks of Disability Studies and feminist theory undergirded this work, informing not only the study's initial design, but also the methodological choices I made throughout data collection and analysis. These theoretical frameworks characterize this dissertation's commitments to centering marginalized voices and accounting for multiple, situated "truths," and adhering to the study's participatory research aims. As this dissertation inquired not only about the "what," but the "how," Chapter 5 discusses methodological findings about doing participatory, qualitative research with this unique population.

Site and Population

This dissertation research took place at a private, four-year university in the United States, (Central University, or "CU")[3] within a postsecondary education program specifically for students with intellectual and developmental disability (IDD) labels, The Alma Mater Program, or "AMP." AMP was run by the director and staff of The Center for Inclusive Higher Education, established by members of the CU Board of Trustees to support research, programming and technical assistance for individuals with intellectual and developmental disabilities wishing to pursue postsecondary education.

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[3] The name of the university, research center and postsecondary program have all been changed to maintain confidentiality.

The Alma Mater Program was part of a second cohort of twenty-five Transition and Postsecondary Programs for Students with Intellectual Disability (TPSIDs) across the United States, and, along with the other twenty-four programs across nineteen states, was awarded part of a $9.8 million federal grant for FY2015-FY2020 (National Coordinating Center Accreditation Workgroup, 2016). AMP provides an alternative pathway to accessing postsecondary education for students who may not otherwise meet traditional university admissions requirements (Hart, Grigal, Weir, 2010). Interested students apply to the program by detailing who they are as learners, the kinds of supports they may need in accessing a college experience, recent high school evaluations, and two letters of recommendation. They also complete an in-person interview with program staff to determine if the AMP program's philosophy and structure fit with their academic, career and life goals. The AMP staff offer admission to students based on capacity, fit and if AMP and CU can provide the kinds of supports that will allow the students to be successful. As of Fall 2018, students in the AMP program became eligible for federal financial aid, as AMP applied for and was approved as a "Comprehensive Transition Program," or "CTP." AMP students pay for college via a variety of means, some utilizing private family funds, state Medicaid funds, SSI funds, or a combination of the aforementioned sources. The AMP program is designed to be a 4-year program: three years of coursework and the final year participating in an internship program where they gain employment experience in their chosen fields. Most AMP students take an average of two courses per academic semester and have access to the entire university catalogue. In addition to the inclusive academic courses, AMP students have the option of signing up for weekly seminars each semester, attending these with primarily other AMP students (though they are open to all students at CU). Example themes of AMP seminars include: dating and relationships, cooking, job interviewing, and developing

personal narratives. AMP students receive any disability-related accommodations from the university's office of disability support services and are also paired with a paid mentor to support their academic access. AMP students are also paired with unpaid peer partners from the "Student-2-Student" program —matriculated students who also attend CU—to facilitate their social inclusion by attending sporting events, sharing meals, going for coffee, or participating in other campus activities whether AMP-organized or not. AMP students audit their courses and though AMP is not a degree-granting program, students receive certificates of completion from CU's college where other part-time, non-matriculated students take classes (for example, non-traditional students who may already be working full-time and pursuing their education in addition). Though they do not receive letter grades, AMP students earn the same certificates as all other non-matriculated students.

I selected the students enrolled in the Alma Mater Program (AMP) at Central University (CU) for several reasons. First, as a model TPSID program, AMP had already met criteria put forth by The Higher Education Opportunity Act of 2008 (HEOA), committing to implementing some or all of the promising practices outlined by the HEOA including: access to inclusive courses, participation in paid employment, and earning some kind of credential upon exiting the program (Grigal, Hart, Smith, Domin, & Weir, 2016; National Coordinating Center Accreditation Workgroup, 2016). I chose this single site to capture a snapshot of a moment in time for these participants.

Participants

The ten students who participated in this study had been enrolled in the Alma Mater Program ("AMP") for at least one semester and, as mentioned above, had already begun to explore crafting their own personal narratives in a seminar-style setting. To be eligible for AMP,

students were required to have a diagnosis/label of intellectual disability (ID). This could include, among others, labels such as Down syndrome (DS), Williams syndrome (WS), and Autism Spectrum Disorder (ASD), however, specific disability documentation or disclosure was not necessary for participation in this study. Other than the students in this study who identified as individuals with Down syndrome (arguably a "visible" disability), I did not actually know the specific labels my participants carried unless the students chose to disclose them. Incidentally, only the students with Down syndrome, Billy and Victoria, claimed their specific labels since World Down Syndrome Day fell within the data collection period and they attended local celebratory events to mark the occasion. Jim and Johnny were the only other participants who referenced having disabilities, though they did not name them nor claim any particular disability identity. The remaining six participants made no reference to their own disabilities throughout the data collection period.

Recruitment and Selection

Before the data collection began, I employed a purposeful sampling technique and reached out to AMP staff to identify between seven to ten students who might be interested in participating in this study. This mostly-formed group of students already engaged in personal narrative work emerged as a natural group with which to collaborate. The study was described as an opportunity to share their experiences and perspectives about college, and take photos to represent those experiences. Invitations to participate (See Appendix A: Invitation to Participate) were sent to AMP students via email. Ten AMP students expressed initial interest, while ultimately nine students attended our group meetings on a regular basis (one participant, Joseph, attended sporadically because of extenuating personal circumstances.) Table 1 includes a list of this study's participants: their name, age, gender, race/ethnicity, and year in AMP. Below the

table are short introductions to each participant. As a group, the students who participated in this study and those in the AMP program broadly did not reflect a typical population of traditionally-enrolled undergraduates in terms of age. Most first-year students at CU enroll straight out of high school, but Shannon, Billy, and Victoria were the only students from this study whose ages and year in AMP reflected traditionally-enrolled undergraduates. Considering how much older Joseph was than the other participants (who were all 30 years old and younger), it's not surprising that his participation in the study ended up being sporadic. As of Fall 2018, the AMP program enrolled 77 total students, 62.3% male and 37.7% female, while CU broadly reported an undergraduate student population of 15,252, 46.1% male and 53.9% female. In terms of racial/ethnic demographics for undergraduates, The AMP program reflects less racial/ethnic diversity when compared with CU, with 31.2% of students self-reporting as non-White within AMP, compared with 43.1% of CU's entire undergraduate student body identifying as non-White.

Table 1

Participant Demographics

Name	Age	Gender	Race/Ethnicity	Year in AMP
Booker	23	M	African American	1
Billy	19	M	White	1
Chris	22	M	White	1
Jim	28	M	White	3
Johnny	29	M	White	2
Joseph	44	M	Hispanic/Latino	1
Kerianne	28	F	White	2

Lawrence	25	M	African American	3
Shannon	18	F	White	1
Victoria	21	F	White	2

Booker. Booker, a tall, lanky guy with dreadlocks that were often dyed orange to show his school spirit, could always be seen walking around CU's campus with his headphones in his ears. It seemed as though he walked to his own personal soundtrack, often quoting song lyrics that held particular significance in the moment. He attended high school locally (the same high school as Lawrence, another participant), and in addition to holding two part-time jobs at a local grocery store and clothing and goods donation store, was an active member of his church and its community chorus. Booker interacted with most people with an amiable ease and had a goofy sense of humor, finding jokes in sometimes unexpected places. He could be described as a CU "super fan," sometimes attending multiple university sporting events in one day, and always updating the group about the latest lacrosse or basketball stats. Booker joined the study during his first year in the AMP program, attending many program social events and often palling around with Jim and Shannon. Booker had inside jokes with the AMP staff, frequently stopping by their offices to say hello.

Billy. Every room Billy entered, he did so with flair, and often with an exuberant "Hey guys!" or "I'm here!" He always had a clean, stylish haircut and sported trendy dark-rimmed glasses. Billy had just enrolled in CU when deciding to participate in this study, though he was a lifelong supporter of CU athletic teams and another big basketball fan. As discussed in the data, Billy was the manager of the CU men's basketball team, an opportunity he was offered since his parents were friendly with the coach and his wife. Throughout the data collection period Billy

became a very visible student in the AMP program, being featured in local and campus news stories as well as film student documentaries.

Chris. Chris was a student very interested in culinary arts, often discussing his experiences in CU's "Food Studies" program, and his future goals of attending the local community college to pursue a culinary path. He held two part-time jobs during the data collection period, at Dunkin Donuts and working in the kitchen at the local zoo, and shared his extensive knowledge of prepping for large catering events that the zoo often hosted. Because Chris also had a driver's license and a car, he had greater access and autonomy to networks beyond the AMP program and CU, but, perhaps due to his work obligations, had fewer opportunities to participate in social events either inside or outside of the program.

Jim. Along with Lawrence, Jim was the most experienced student who participated in this study, in his third year of the AMP program during the data collection period. A natural leader in group discussions, Jim was never shy about sharing his thoughts and opinions, adding richness and complexity to the data. Jim worked on disability advocacy projects with one of CU's research institutes and traveled with a faculty member to a national assistive technology conference. Jim was close with Booker, Shannon, Johnny and Lawrence who, if Jim wasn't immediately present at the start of our focus group sessions, would often inquire "Where's Jim?" As the unofficial technology guru of the group, Jim often helped other students (and helped me) troubleshoot issues with accessing Wi-Fi, sharing photos, or locating emails about AMP events.

Johnny. Mild-mannered and earnest, Johnny was enrolled in his second year in the AMP program and often shared how happy he was to be there. Originally from the West coast, Johnny was a self-described "gym rat" who enjoyed playing and watching sports, particularly basketball. Clearly envious of Billy's opportunity to serve as the basketball team's manager, Johnny

expressed a desire to take on a similar role. While not always the most vociferous participant, Johnny often sat near me and whispered his contributions to group discussions. Before attending the AMP, Johnny attended a day program at the local community college specifically for adults with intellectual and developmental disability labels, sharing how much more he enjoyed AMP.

Joseph. Due to extenuating circumstances, Joseph was not able to attend many of the focus group meetings. When he did, his contributions were clear and to the point, demonstrating a no-nonsense approach to his coursework. Joseph was a non-traditional student due to the significant age different between him and the rest of the AMP cohort, perhaps contributing to his prioritization of coursework rather than social events.

Kerianne. Kerianne was a quiet, thoughtful student who, though not always the loudest voice in the room, was open and willing to share her thoughts when asked. Unlike most of the other participants who lived with their parents, Kerianne lived in her own apartment, renting the space above her brother's apartment in a neighboring town, not far from CU. Like Johnny, Kerianne previously attended the same community college day program, sharing Johnny's assessment that it was "boring." Kerianne was an avid crocheter who, when I shared the news of my pregnancy with the group, offered to make me a baby blanket.

Lawrence. Lawrence and I shared a love of 1990s hip hop and R&B music. He could often be seen dancing in the hallways to a Prince song or reciting the lyrics to the theme from "The Fresh Prince of Bel-Air." When the group attended a local hockey game, Lawrence's enthusiastic dancing earned him a few minutes on the jumbotron, with other AMP program and Student-2-Student attendees cheering him on. Lawrence highly valued his cultural heritage, often wearing traditional African head garments or sashes to our focus group meetings and sharing his admiration for Martin Luther King, Jr. and Malcolm X. He was an active member in his church,

attending each Sunday in vibrant-colored suit, hat, and tie combos.

Shannon. Enrolled in her first year in the AMP program, Shannon took advantage of every opportunity the AMP program had to offer, jumping into college life with both feet. Since her mother worked at CU, Shannon was familiar with campus and, though she initially described herself as "shy," really came out of her shell as the data collection period progressed. She often came to the focus group sessions dressed in CU's colors, showcasing her school spirit in anticipation of high-stakes basketball or football games. Towards the end of the data collection period, Shannon was preparing to live in the dorms during the next semester, anxiously awaiting her dorm assignment and speculating what the experience might bring.

Victoria. Though perhaps presenting as slightly reserved, Victoria was a thoughtful, contemplative student, fiddling with her glasses as she considered how to respond to various group discussion topics. She participated in many activities such as Special Olympics and musical theater, and was active in the local Down syndrome community. Enrolled in her second year in the AMP program, Victoria took hands-on, participatory classes such as Zumba, yoga and cooking.

Participant Risks and Benefits

Participants were asked to share experiences from their lives that included academic challenges, barriers to access and participation, instances of social exclusion or other potentially sensitive topics. I endeavored to create and maintain a safe and collaborative space and reminded participants that they were not required to share things with which they were uncomfortable. The design of the study was such that students could elect what to document and represent, and thus have control over the information they chose to share. In being involved in a research project where students were documenting and representing their college experiences and sharing that

information with their program's director and staff, their findings had the potential to inform decision-makers who had the power and resources to enact change within their lives and the lives of students in future AMP cohorts (Jurkowski, 2007; Paeiwonsky 2011; Prohn 2014). Additionally, other studies utilizing photographs as visual supports reported that participants experienced increased pride, confidence and a sense of ownership throughout the process, while also feeling rewarded and motivated to continue with each photo shared (Jurkowski, 2007). The benefits of this study outweighed the risks as they included privileging student perspectives and contributing knowledge to a burgeoning field of inquiry to hopefully improve the lives and college experiences of future students with intellectual and developmental disability labels. As noted by researchers undertaking similar studies (Paeiwonsky 2011; Prohn 2014), inquiries involving what Institutional Review Boards (IRBs) classify as "vulnerable populations" such as participants with "cognitive impairments," present additional considerations with which this study had to contend. Though this dissertation assumed a Disability Studies-informed approach to study design, data collection, and analysis that presumed competence in its participants to represent and be consulted about their own lives (Biklen & Burke, 2006; Charlton, 2006; Oliver, 1992; Petersen, 2011; Shapiro, 1993; Zarb, 1992), specific steps were taken to establish and maintain informed consent and discuss photography ethics with participants (See Appendix B: Photography Ethics Training). Though students' social media accounts were not included as sources of data, some students elected to bring up pictures shared via their social media accounts or share social media posts during our meetings, thus bringing some social media content into the focus group space.

Informed Consent Procedures

  I obtained IRB permission to conduct this study by working with my dissertation chair to

detail the study's rationale, methods and procedures for data collection and analysis, and plans to garner informed consent and ensure participant confidentiality. The application underwent several revisions and was ultimately approved. To ensure that participants understood the potential risks and benefits of participating in this study, my approach to establishing informed consent was careful and thorough. With permission from Dr. Katherine McDonald, I adapted a combined Consent/Assent form she had developed for use in a previous study with participants with intellectual disability (See Appendix C: Consent/Assent form; McDonald, et. al, 2016). This form was written in accessible language and included pictures to support the text. During our initial meeting before data was collected, I distributed the form to the students and read it aloud. Then, I fielded questions and suggested the students take the form home and share with parents, staff members or other trusted individuals before deciding to participate. For the 6 students with legal guardians, those additional signatures were garnered. Additionally, throughout the semester, I checked in with the students about their continued participation, reminding them that it was entirely voluntary, they had complete control over what information to share with me and the group, and they could elect to withdraw at any point. As the study was informed by theoretical frameworks that maintained participatory and democratic aims, these commitments reinforced the consent process.

Procedures

Data Generation

This study utilized photographs as visual supports to facilitate discussions about the college experiences of the student participants. Data were generated through audio-recorded and transcribed weekly focus group sessions as well as my accompanying field notes, research memos and participant observations. By the end of the data generation period I had collected

fifteen hours of audio recordings resulting in nearly 300 pages of transcribed data. Additionally, my participant observation field notes and research memos yielded an additional 100 pages of data. As noted previously, since this study explicitly inquired into the methodological implications of conducting research with participants with IDD labels, my research memos were included as part of my overall data set and analyzed for themes (Aldridge, 2007; Conder et. al, 2011; Noffke & Somekh, 2005). Building on previous work with college students with intellectual and developmental disability labels by Paeiwonsky (2011) and Prohn (2014), this study's use of photographs as visual supports allowed participants to share their college experiences in ways beyond only talking about them. Cognizant of the cited methodological challenges to conducting qualitative research with participants with intellectual and developmental disabilities, specifically around consent, communication and autonomy, (Arscott, Dagnan & Stenfert Kroese, 1999; Beail & Williams, 2014; Booth & Booth, 1996; Clarke, et. al, 2005; Harris, 2003; Jones & Stenfert Kroese, 2007; McVilly et. al, 2008; Nind, 2008; Redd, 2004), my goal was for students to document and represent different aspects of their college experiences and use those pictures as discussion-starters and organizers during focus group discussions. However, in wanting to center the students' voices and garner their understandings of their college experiences, I did not conduct my own analysis of their photos. My decision to not analyze the students' photos was to remain faithful to how they chose to narrate their worlds. Though I believe the photos would have complemented the data presented herein, the students would have had to waive confidentiality. I did consider this possibility in the initial design of my study, and weighed the risks and benefits of doing so. My ultimate decision rested in my sense that though I might feel confident in designing and implementing a study that set a high ethical standard, I couldn't predict how the eventual findings and analysis would be taken up by this

dissertation's readers. In the final chapter of this dissertation I discuss the potential limitations of this decision and what might have been lost or gained had I acted otherwise.

I initially designed and sought to implement this study via an adapted Participatory Action Research (PAR) approach organized into the following phases: Phase 1, "Plan and Practice," (Generating topic ideas for photos and conducting ethics training); Phase 2, "Document" (Taking pictures); Phase 3, "Share and Discuss" (Presenting pictures to the group and discussing their content); Phase 4, "Categorize and Name" (Captioning photographs and organizing similar photos into categories); Phase 5, "Create," (Making a group product from their collective photographs) and, Phase 6, "Reflect and Celebrate" (Discussing the project's successes and challenges and sharing their product with peers, program staff and family members). The PAR process employed for this study was "adapted" to capture a snapshot of the students' semester and better align with the research questions. However, as happens when studies move from inception to implementation, my planned PAR process quickly evolved from its original iteration, and, upon writing memos after each focus group session, I made several methodological decisions to remain responsive to the students' needs while staying as close to my participatory aims as possible. Though their photographs facilitated the representation and discussion of students' college experiences, certain access challenges arose that incited new methodological decisions and directions. In fact, though a PAR framework informed the study's intial design, what happened in practice did not align with PAR practices. While I describe the data collection process that occurred in the reminader of this chapter, Chapter 5 presents methodological findings and implications in greater detail while Chapter 7 discusses future research directions and implications for participatory scholarship.

Timeline. Figure 1 represents the data collection timeline at a glance. As evident from the

graphic, the six phases did not actually unfold as a cycle, with one phase finishing before the next began. Rather, the activities within Phases 2 and 3 permeated throughout most of the data collection period. That is, the students took pictures weekly (Phase 2: Document) and talked about these pictures weekly (Phase 3: Share and Discuss). At key moments throughout the data collection period, I made methodological decisions that ultimately changed the project from its original iteration. While I always communicated with the students about our group process, looking to them for ideas and feedback about how things were working or not, I did not frame these discussions in research jargon or necessarily share with them that what we were doing was somehow a "change" from what I had originally proposed. I introduced the study and continually reinforced its objectives in the same way throughout: to hear from them about their experiences in college. My methodological memos served as spaces to propose changes to the study's implementation, and I describe these key moments in the narrative below. I was not always the decision-maker in these key moments, but rather sought to respond to the students' preferences in picture-taking and sharing activities as well as focus group communication and participation.

Figure 1

Data Collection Timeline
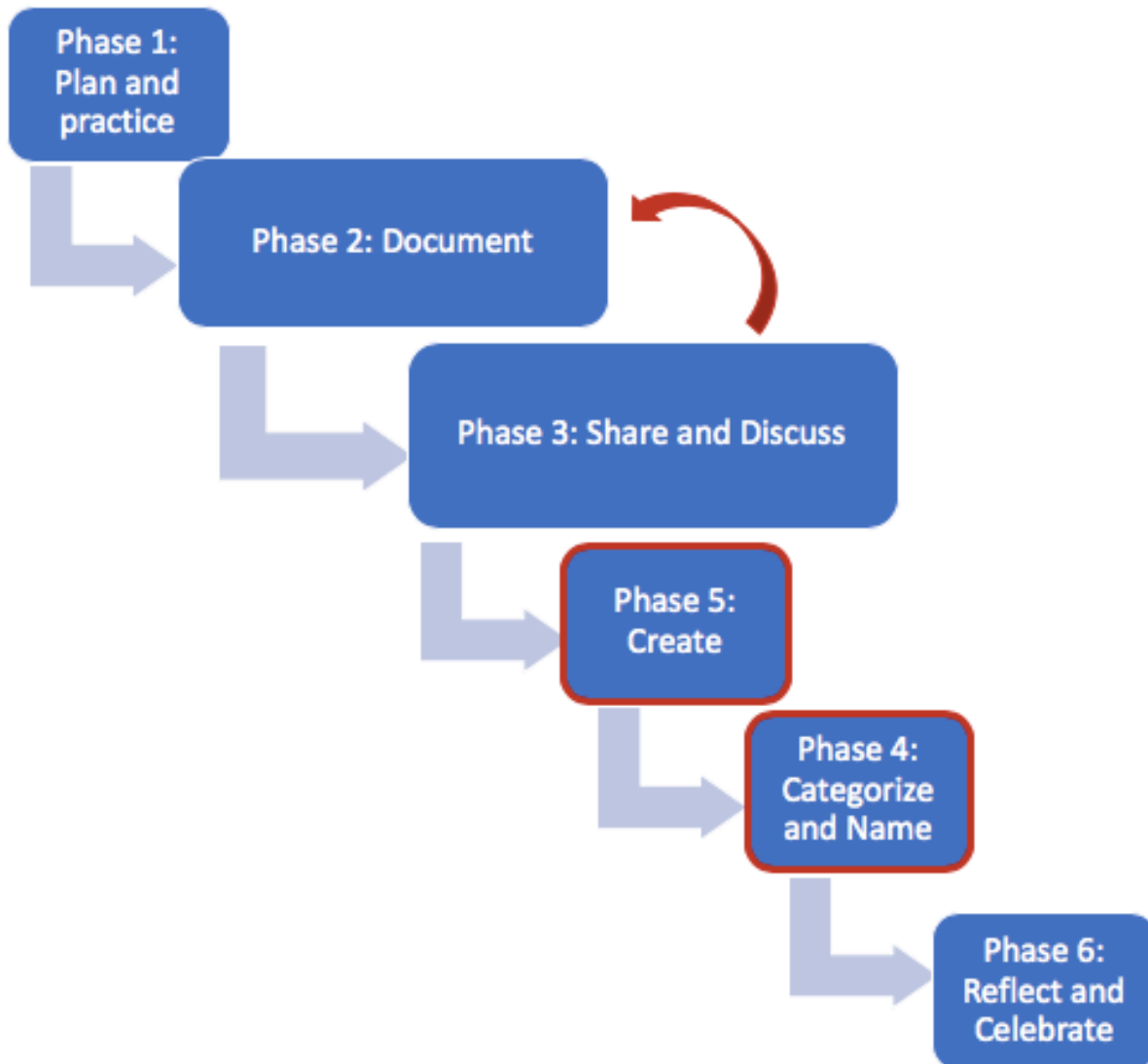
At the first focus group meeting, I introduced myself to the students (a few of whom I had met before briefly), and introduced the dissertation project and its goals. During this Phase of the PAR Cycle, "Plan and Practice," I facilitated a brainstorming session with the students about what constitutes research. Then, upon co-generating a definition of research, we discussed different ways to collect data to tell stories, zeroing in on photographs as a form of data. Next,

we discussed the ethics of taking photographs and role-played scenarios about asking for permission and what to do depending on the response. At the end of the first session, the students and I co-generated topics around which to take pictures to represent their college experiences including "academic life," "friendships," and "social activities."

During the week between focus group sessions, the students engaged in Phase 2 of the data collection process, "Document," documenting their college experiences around the chosen topic and bringing in those pictures to share with the group. In an effort to allow the whole group to view each person's pictures, we initially established that the students would either text or email me their selected photo(s) to share and I would project them on a screen in our meeting room. Then, for Phase 3 of the data collection process, "Share and Discuss," each student took turns describing their photo(s) and addressing questions or comments from other group members about the subject of the photo(s). I endeavored to provide a flexible structure to the focus group discussions, asking each student open-ended questions about the photos they elected to share, and eliciting greater detail about the photo's subject and the student's rationale for taking it and sharing it. Thus, the data included for this study were those data from focus group meeting transcribed audio recordings, field notes from participant observations, and my methodological journal entries. I did not analyze the photos themselves, but rather analyzed what the students said about the photos. However, challenges arose for some participants in accessing their devices, or figuring out how to share their photos with the group. Additionally, some students did not know or have access to their login information for things like university email, their App store or iTunes accounts, or their social media accounts.

Lawrence, Jim, Shannon, and Booker proved the most tech-savvy participants, boasting strong social media presences on Instagram and Facebook and easily sharing their pictures with

me during the focus group sessions. Though this study did not explicitly use students' social media accounts as sources of data, many students elected to bring up their Facebook or Instagram accounts to find and broadcast their weekly photos, since that's where the pictures "lived." In fact, in efforts to both allow participants to share photos and stories in ways that were accessible and convenient to them while also avoiding the exclusion of students without social media accounts, I decided to abandon the weekly photo "topics" and instead allow participants to select any photo to share from either their device libraries or social media accounts. In seeing that Jim, Shannon, Booker and Lawrence often created digital collages of images they posted on their social media accounts, I suggested that the rest of the group follow suit, and, in Phase 5 of the data collection process "Create," create their own digital collages to represent their year in AMP at CU. I enlisted Jim and Shannon to lead a tutorial about different programs or apps to make digital photo collages, placing them in expert roles. Taking the "Create" phase a step further, Jim elected to curate his social media photographs and compose a digital slideshow set to music. He debuted the slideshow for the group during our second-to-last focus group meeting and then screened it for all attendees at the program's end-of-the-year celebration a few weeks later, sending everyone home with their own copy.

Some weeks, however, pictures took a back seat to pressing student concerns or priorities, and the discussion just happened, without the support of pictures. During these sessions, conversations often began with students sharing their respective weekend activities, talking about upcoming AMP events they planned to attend, or just reporting out on general life happenings. Through the musings in my methodological memos, I vacillated between wanting to keep the focus group sessions on the topic of college and adhering to my democratic, participatory aims of following the students wherever they opted to take the conversations.

Therefore, since my initial PAR-informed design necessitated more structure to the data collection and analysis process, I abandoned this moniker and framework to be more responsive to student priorities. In the end, the focus groups did a little of both—sometimes centered entirely on the themes that will be discussed in the next chapter and sometimes veering into new and seemingly disconnected directions. In fact, these "tangents" or "seemingly non-sequiturs" as I ended up terming them, provide the basis for one of the methodological themes I discuss in Chapter 5.

Though departing from the precise structure of the PAR cycle early in the study, some aspects that proposed approach remained. Phase 1, "Plan and Practice," Phase 2, "Document," and Phase 3, "Share and Discuss," happened as were proposed. Phase 4, "Categorize and Name," and Phase 5, "Create," ended up flipped (as noted by these phases being outlined in red in Figure 1), as the students first decided to create digital collages of selected photos to represent their first year in the AMP program at CU. Taking a cue from Paeiwonsky (2011), I facilitated a discussion in which the students then generated title ideas for their collages during Phase 4, "Categorize and Name," effectively coding their collages as data and identifying common themes across each one. Phase 5, "Create," manifested in an additional way when Jim decided to make a slideshow of his favorite photos taken throughout his time at AMP, and set it to music. A partial Phase 6, "Reflect and Celebrate," happened during the program's end-of-the-year celebration when Jim shared his slideshow with other AMP students, agency support staff persons, and AMP staff and peer partners. Set to the songs "Closer" by The Chainsmokers, and "Purple Rain" by Prince (as a nod to Lawrence, a self-proclaimed Prince super fan), the slideshow video was a little more than five minutes in length and included photographs the entire group had taken over the course of the academic year. In fact, during our second-to-last focus group meeting, another partial Phase 6,

"Reflect and Celebrate," Jim previewed the slideshow for our group and, as it played, the students told me about the photos that were included and reminisced about the happenings of the past year. Jim remarked how he planned to "make one of these next year also."

Data Analysis

The sources of data that comprised my overall data set included: 15 hours of audio recordings from our focus group sessions resulting in approximately 300 pages of verbatim transcriptions, 50 pages of field notes from focus group sessions, 25 pages of participant observation field notes, and 25 pages of methodological journal entries. The analysis of this data set followed the principles of phenomenology and Interpretive Phenomenological Analysis (IPA) put forth by Husserl (Merriam, 2009) and Smith and Osborn (2009), and was interpreted via the identified theoretical framework of Disability Studies. Though setting out to conduct a Participatory Action Research (PAR) project to not only collect data but also analyze it (e.g. I had intended to facilitate specific data analysis exercises with my participants), this did not occur in great depth. As noted in the Data Generation discussion above, to remain responsive to participant priorities and preferences in terms of what to discuss on any given day, and what photos to share with the group, the structure of the focus group meetings evolved from my initial vision. As such, I did not explicitly engage participants in deep analysis of the photos they elected to share with the group, but rather facilitated flexible conversations about said photos, attempting to elicit participants' thoughts and reflections about the photos selected, their subject(s), their motivations for taking them and motivations for sharing them. At the point during the data collection period where I attempted to facilitate collective analysis conversations, I was becoming increasingly aware of the perhaps-too-central-role that I was assuming within the study. As I discuss in Chapter 5, 6 and 7, my role as researcher began to resemble that of

teacher or authority figure and thus the particularly heavy-handed activity of facilitating analysis conversations seemed to me to exacerbate a methodological challenge I was actively trying to mitigate. The one exception was during our ninth focus group meeting where I engaged the students in a conversation about naming the photo collages they had each made, thus conducting some initial thematic analysis of the entire corpus of their photos:

> KV: Cool, so you know how sometimes when people put up photos they also include descriptions of what's going on in the picture? So, if we were to like "caption" that collage… to describe something that represents it… does anyone have ideas about how you would write a caption for that collage?
>
> Shannon: Like… I was like "This was my first year at CU."
>
> Booker: "All the random stuff we did this year" (Laughs)
>
> Jim (Laughs): Yeah! "Random stuff."

Consistent with the findings of Prohn (2014) and Redd (2008), my presence as the researcher and the focus group facilitator contributed to the co-construction of the narratives generated. Additionally, as I was the one writing memos, transcribing, and creating codes and categories, it ultimately positioned me as a more significant actor in the inquiry process than I originally intended. Methodological findings about the role of the researcher are included in Chapter 5.

As described in the Theoretical Frameworks section in Chapter 1, I utilized a phenomenological approach to data analysis to remain flexible to how my participants made meaning of their social worlds. In phenomenology, the researcher is not presumed to be detached from her process, and must wrestle with her own positionality and subjectivity (Creswell, 2012). I kept a methodological journal to "bracket" how I was experiencing the data collection process

and the assumptions I was making or tensions that I felt, writing memos after each focus group or participant observation to stay attentive to how my identity and commitments contributed to the meaning I was making (Creswell, 2012; Smith & Osborn, 2009). I undertook a three-step, inductive coding process informed by Smith and Osborn's (2009) Interpretive Phenomenological Analysis (IPA) approach to develop themes around which to write my subsequent data chapters and discussion. I selected an IPA system of coding because of its commitment to striking a balance between valuing participants' understandings of their own experiences whilst also acknowledging the role of the researcher in co-constructing and interpreting the data collected (Smith & Osborn, 2009). Additionally, IPA is uniquely suited to investigating questions that are under-researched or what Smith and Osborn (2009) call "novel…where the issues are complex and ambiguous" (p. 231). I coded on paper, by hand, cutting out segments of data and physically moving them around my kitchen table to try to see the patterns or relationships within. As I am a visual learner, interacting with my transcripts on the computer proved challenging since there was just too much data to wrangle. The process of coding by hand and physically moving data excerpts helped me to remain organized and methodical throughout my analysis process while also flexible enough to easily make changes

Three-Step Analysis Process

Step 1: Initial reading of data and identifying segments of data relevant to the study. After transcribing the recordings from my focus group meetings, I did a detailed reading of the entire data set which included said transcripts, field notes taken during and after each focus group meeting, methodological journal entries and field notes from participant observations. Within the entire data set I identified the areas of my data relevant to my research questions and prepared to look at these more closely. Within the relevant segments, I then developed two tracks of data:

Content and Methodology.

Step 2: Open coding of the data I identified in Step 1 to develop categories. Within each

track, Content and Methodology, I coded the data line-by-line to identify broad categories. For

the data related to Content, these included: Relationships, Education, and Activities. For the data

related to Methods, these included: Collecting data in focus groups and the role of the researcher.

I used different colored markers to highlight the abovementioned categories and read through a

second time to catch instances I might have missed.

Step 3: Inductive coding of each category and developing themes within each. Next, I

undertook an inductive coding process to identify emergent themes within each category.

Starting with the Content track, I examined data within each of the categories, one at a time,

similar to the open coding process of highlighting, organizing, and reducing. However, the

purpose of the coding in this step was to develop descriptive themes about my findings. I

conducted the same process with my Methods findings. Within the Content findings I developed

four themes: 1) Participating in program-organized social activities, 2) Different-looking

friendships, 3) Accessing academics with support and 4) Defining college. Within the Methods

findings I also developed four themes: 1) Seemingly non-sequiturs, 2) The role of support, 3)

Researcher as teacher/authority figure, and 4) Flexible data collection decisions.

Once the thematic findings were presented across my two data chapters, I considered

those findings through the theoretical lens employed for this study, Disability Studies, and

discussed the new stories the data communicated in Chapter 6. This chapter was the most

challenging to write both technically and philosophically. This theoretical lens added layers of

meaning to the data, necessitating a close, analytical discussion. Additionally, how my

participants represented and made meaning of their own college experiences often conflicted

with how Disability Studies interpreted those same experiences. In Chapter 6, I wrestled with how to represent these tensions in a way that could both value what my participants said their college experiences meant and what alternative interpretations of those experiences the theoretical framework uncovered.

I did not conduct member checks with the participants in my study, which rightly deserves acknowledgment and rationalization. Upon proposing this study, I anticipated that after I transcribed, coded and analyzed my data, I would set-up either face-to-face meetings with my participants or Skype/FaceTime conversations to chat about how I represented my findings to garner their input and feedback. I ultimately decided against doing this for a few reasons. First, these data captured a very specific moment in time for the students in this study. Many were first-year students in the AMP program whose lives and worlds were steadily changing and this dissertation lived very much within one academic semester. By the start of the next school year, students' social networks and social relationships changed, sometimes their living situations changed (two participants moved into the CU dorms), and some moved from taking classes to participating in internships. I wanted to maintain the integrity of this school year, this semester, and this research space in which these data were generated, and trusted that my participatory, inclusive, iterative design possessed sufficient built-in-member-checks if you will, to always go where the students led me.

Organization of The Remainder of This Dissertation: The What, The How, The Why and The So What?

In Chapters 4 and 5 of this dissertation, I present findings in relation to this study's first two research questions. Chapter 4 includes findings about the study's first research question, "The What": How do students with intellectual and/or developmental disability (IDD) labels

describe and represent their college experiences? I discuss the four most salient themes and briefly put them in conversation with extant literature. Chapter 4's themes are: 1) Participating in program-organized social activities, 2) Different-looking friendships, 3) Accessing academics with support, and 4) Defining college.

Chapter 5 presents findings about this study's second research question, "The How": What does inquiring into the experiences of college students with IDD labels teach us about doing research with individuals with IDD labels? The themes discussed are divided into two sections: 1) Collecting data in focus groups and 2) The role of the researcher. In the first section about collecting data in focus groups, I first present methodological findings about seemingly non-sequiturs: instances where students changed topics unexpectedly, interrupted each other, or took the discussion in a new direction. Also in this section, I discuss the role of support across two contexts: 1) Between students and their support staff and 2) Among the students themselves. In the second section about the role of the researcher, I discuss findings about: 1) Researcher as Teacher/authority figure, and 2) Flexible data collection decisions.

Chapter 6, "The Why," interprets these findings through the chosen theoretical lens of Disability Studies, discussing the tensions that arose when theoretical interpretations of the students' experiences sometimes conflicted with their own understandings. Through this additional layer of analysis, Chapter 6 also attempts to answer this dissertation's third research question: What does inquiring into the experiences of college students with IDD labels teach us about inclusive postsecondary education?

Chapter 7, "The So What?" concludes this dissertation by summarizing each data chapter, discussing this study's limitations, and proposing its larger implications for the field of inclusive postsecondary education, for Disability Studies scholarship and for participatory qualitative

research. I conclude Chapter 7 by considering new and future directions for research.

Chapter 4

Content Findings

This chapter will discuss findings about this study's first research question: How do students with intellectual and developmental disability (IDD) labels describe and represent their college experiences? Anticipating that the students would highlight different aspects of their college experiences, I left this research question intentionally broad to allow for refinement throughout the data collection period. As noted in Chapter 3, I designed this study to center the often-marginalized voices of students with IDD labels to represent their own college experiences (O'Brien, 2009; Paeiwonsky, 2011, 2014; Prohn, 2014). Informed by Disability Studies and feminist theory, this study employed a Participatory Action Research (PAR) approach to data collection while drawing from the analytic principles of phenomenology and Interpretive Phenomenological Analysis (Smith & Osborn, 2009). Additionally, asking student participants to document their college experiences with digital photographs acted as visual supports and conversation organizers for focus group discussions (Aldridge, 2007; Booth, 1996; Mathers, 2005). The photographs taken and shared throughout the data collection period helped facilitate the students' discussions about what college meant from their perspectives. I did not conduct my own thematic analysis of the students' photographs but rather used them as visual supports to elicit how they understood and made meaning of college. Utilizing an Interpretive Phenomenological Analysis approach, I analyzed transcripts from the focus group discussions in which the students described their photographs, yielding the following themes around which the students framed their experiences: 1) Participating in program-facilitated social activities, 2) Different-looking friendships, 3) Accessing academics with support, and 4) Defining college. Below I include data excerpts from the focus group transcripts to illustrate each theme while also

putting them in conversation with extant scholarship about the college experiences of students with IDD labels.

Participating in Program-Facilitated Social Activities

The college experiences of most of the students who participated in this study were characterized by full social calendars (Prohn, 2014). They seemed to always be discussing the next upcoming event. Thus, the photographs that the students elected to share and discuss in our focus group sessions were most often taken at a group social event where their access and participation was facilitated in some way by the structures of the Alma Mater Program. Some events were spearheaded by the AMP program staff, while others were organized and carried out by the Student-to-Student peer leaders and peer partners. Participants shared pictures from seasonal activities such as apple picking, ice skating, skiing, or trips to a water park, community activities such as going to a local hockey game or playing miniature golf, and of course myriad university sporting events such as lacrosse games, football games and basketball games. Below, Jim described the pictures that comprised a digital photo collage he made, while Shannon and Billy added to the discussion:

> Jim: Yeah, so a lot of these are from events that we've done, so, I will go through. So, start with this one. So, this one started—this was at a football game, this was at a movie, football game, apple picking, that was at Burke Hall before it got torn down, meeting the Senator at that one, Burke, Burke, Halloween party, Halloween party, Halloween party…
>
> KV: Where was the Halloween party held?
>
> Jim: Burke.
>
> KV: Oh ok.
>
> Jim: Umm… that one, I forget. Basketball game, basketball game, bowling, skating,

football game, ice skating, football game, basketball game, and… basketball game.

Shannon: I went to all the basketball games.

Billy: Me too.

Shannon added how, for her, it was often difficult to decide which pictures to share with the group, since she and other students took so many at the various social events: "Reba takes a lot too, she's always like 'Let's take pictures!' And I take so many, like, everywhere. My mom was like, 'Take a picture at the Bishop game,' and I'm like 'Yeah, that won't be hard!' There were so many people there. This is how many people" (OC: Shows photo to me on her phone of a full stadium.)[4] CU's game against Bishop University[5], a long-time basketball rival, was highly-anticipated by most of the AMP students, none more so that Shannon: "I was going crazy! I was standing the whole time! I was like 'Everyone up in the student section!'" This and many focus group sessions often began with the students catching me up on the latest university sports statistics, often highlighting the men's basketball team because CU was a frequent participant in the NCAA tournament. Since basketball occupied a privileged status within the larger campus culture of CU, attending games and sitting in the "student section," while perhaps assumed for traditionally-enrolled students, represented a key in-group experience for the AMP students. Shannon held season tickets for the CU men's basketball games and was a fervent team supporter. She described one incident where she had to navigate the arena's seating restrictions, and shared how Reba, the Student-2-Student program's peer leader, facilitated access to the student section seating for her and a few other AMP students:

Shannon: So, when we got there, me and Abby and like, Reba…and we went in like the

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[4] Throughout the transcript data I include occasional "observer comments" (OCs) and "expanded field notes" (EFs) to provide context or additional information gleaned from the focus group sessions.
[5] The name of this university was changed to maintain confidentiality.

season ticket line.

KV: Oh, are there different lines?

Shannon: Yeah. We were trying to find 317 because that's where we were, but we like… we had issues… like… they're like, 'you can't sit up here…' and they wouldn't let us, but then like Reba took care of it.

KV: Oh. That's good. What did she do?

Shannon: I don't know what she said because I couldn't really hear that well, but I think she said something like 'They're with us… and they have to sit with us.'

In one focus group meeting before a group trip to see the local hockey team play, I inquired who planned to attend:

KV: So, who's going to the hockey game?

Jim: It's me, Shannon, Lawrence, Reba, Kevin…(trails off)

Booker: I'll be there in spirit.

Shannon: (Laughs) It's no surprise! I mean, I go to everything.

Jim (Laughs): Yeah, I mean it's the same people that go to everything.

In the following session, Jim shared his surprise that Lawrence also ended up attending the hockey game, offering:

Jim: It was very surprising to see Lawrence on Saturday because he doesn't really do any of the events with us.

KV: Oh really? Well that's what someone said about Jamal as well. That he doesn't really do a lot of AMP events. (EF: Jamal is another AMP student who was not a participant in this study.)

Jim: Yeah that's true, he doesn't really go out either.

Though many of the students who participated in this study were frequent event attendees—namely, Jim, Billy, Booker and Shannon—they were aware that not everyone was. The data evidence the students' awareness of "in-groups" within the AMP program of those who "go to everything" and those who have fewer opportunities to access AMP and CU events, often due to transportation access or other responsibilities. Since demographic data about students' socioeconomic backgrounds was not collected, it's unclear if campus event participation trends explicitly aligned with resource availability (money, leisure time, transportation, etc.), however, certain characteristics of specifically Chris's and Kerianne's lives suggest that socioeconomic status may have played a role in their ability to access campus events. Kerianne lived with her family in a small, rural town located almost thirty minutes from CU, making it difficult to come to campus for social events. Chris had his driver's license and his own car, but had two part-time jobs (one at Dunkin Donuts and one at the local zoo), limiting his leisure time. Chris and Kerianne were the participants who most often shared photographs of their lives outside the context of AMP and CU. Below, Chris showed the group a picture he took while at the local zoo. Chris shared pictures of the zoo animals since he had a part-time job working in the kitchen there.

> Chris (Holds up phone to group): I took a picture of the red pandas (EF: Chris works at the zoo doing catering/kitchen kinds of stuff and takes many photos of the animals at the zoo. In fact, these were the primary photos that he shared throughout the seminar. Though given the prompt/guidance of campus-related things, he always brought in pictures of the zoo.)
>
> KV: Red pandas? Wow that's awesome.
>
> Chris: I was at the zoo so I was like, 'You know what? I'm just going to take pictures of

stuff there.' I'm going to send you a bunch of pictures now from the zoo. Because I spend

most of my time at the zoo, so most of my pictures are from there.

Additionally, the photographs Kerianne elected to share were selfies of her smiling for

the camera or scenic shots taken from family members' houses. During one focus group session

when most of the group was talking about attending the recent basketball game, Kerianne leaned

over to me and said:

Kerianne: I went to my aunt's house this weekend. And then I went to my uncle's house.

KV: Cool. Where do they live?

Kerianne: My aunt lives in Newbury. My uncle lives in Covington. And he lives up on

the hill. And we got to see the sunset (OC: Shows picture of the sun setting across a field

with trees in the frame.)

As evidenced above, the students often discussed upcoming social events to see who was

attending, and shared information with each other about various logistics—what time the event

in question started or where they were going to meet to travel together. The data showed that the

students did not often attend these social activities alone, or outside the context of the AMP

program's facilitation and support for their access. That is, someone affiliated with AMP or with

the Student-2-Student program organized a group to attend campus or community events. Jim

remarked how he really liked the social activity organization, crediting this structure with

improving his overall satisfaction with AMP since first beginning the program two years prior:

"Having someone to organize it [social events] is a lot better, and having Reba and Kevin do it is

perfect because they know like, what's going on. And if there's like anything…you can talk to

them and they'll put it right out in the newsletter for you." Reba and Kevin, traditionally-enrolled

students who served as peer trainers in the Student-2-Student program, were the most frequently-

mentioned organizers, doing things like securing group tickets to local sporting events, hosting movie nights at their off-campus apartments, facilitating carpooling arrangements, or navigating access to group seating for university games. During the focus group session before the AMP-organized trip to the hockey game, Jim reminded Shannon that: "You have to text Reba if you want to go." During a later session, Jim described Reba as the lynchpin to organizing a group movie outing: "I know that Booker wanted to go see like, the new *Fast & Furious* movie, so I was like, 'Hey Reba, can we go see the new *Fast & Furious* movie?' And she was like, 'Sure, we can't go on Friday, but we can go on Saturday.' We're going to do it in two weeks." Johnny also shared how much he enjoyed the AMP-organized social activities, wondering:

Johnny: So, if I graduate, do you think… can I… do you think I can still do the events?

KV: Like what kind of events?

Johnny: Like… with Jim…

Jim (Answers for him): The AMP events.

Jim observed that many former AMP students and their families are still on AMP or Student-2-Student email listservs, noting that: "I've seen emails from people that are not even in AMP anymore, and they're like, 'Can you please take my son or daughter off the list?' Carol (EF: one of the AMP assistant directors) sends *everybody* emails about events so you can still go to them."

Participating in campus and community social events with other AMP students and with traditionally-enrolled students in the Student-2-Student program emerged as perhaps the most defining experiences for the students who participated in this study. In the larger context of what it means to go to college or be a college student, attending movie nights at a friend's house or going to a few basketball games might not carry the same significance as it did for this

population of students. As discussed more in the next section, the students in this study reported

high school experiences that were not always positive, often sharing feelings of loneliness or

isolation, and certainly not feeling as if they were part of the "in" group. Research about the

experiences of individuals with IDD labels confirms that their social networks are often limited

to family members or paid support staff (O'Brien, 2009; Prohn 2014; Saarinen, 2016; Villemaire

& Hallquist, 2013). Thus, for these students, accessing and participating in otherwise mundane

college activities are particularly noteworthy and warrant documenting in photographs and on

their social media accounts. However, in collecting data from other postsecondary education

programs for students with IDD labels, a *Think College* survey found that 75% of respondents

noted that on their campuses, students with IDD labels participated in specifically-designed

social activities only with other students with IDD labels (Hart et. al, 2010). The findings from

my study varied slightly. Though AMP students described how their social events were also

attended by traditionally-enrolled students, these students were only those who also participated

in the Student-2-Student program. That is, throughout the data collection period, the students did

not share experiences in which they socialized with traditionally-enrolled students who they met

in class, for example. Their social networks were largely comprised of other AMP students or

Student-2-Student participants. Departing from Prohn's (2014) findings in which his participants

identified multiple "actors" as necessary to facilitate social interactions (e.g. the students

themselves, the campus environment and the postsecondary education program) the social lives

of the students in this study were primarily characterized by events where the AMP program

facilitated their access in some way. In the next chapter, I further discuss these findings as I

wrestle with this study's third research question: What does this inquiry teach us about inclusive

postsecondary education for students with IDD labels?

Different-Looking Friendships

Throughout the data collection period, students elected to share pictures of their friends and their respective social circles. Since most photographs fell into this category, friendship was a frequent topic of discussion. Jim, Johnny and Shannon touched on how their friendships in high school were different than those in college. Jim noted how he "got burned" by his high school friends, so had subsequently cut those ties, while Kerianne, Johnny and Shannon shared how they did not have big social circles in high school:

Johnny: When I was in high school I thought there was like, cliques and groups, so I like, I just kept to myself, because I like… I felt like I didn't fit in.

KV: Do you feel that kind of thing here?

Johnny: No. Well like, I was in special ed a lot, so I thought I was different in many ways, like from everybody else.

KV: Hmm… so, did you have a lot of close friends in high school?

Johnny: No.

Shannon: I didn't either. I mean, people were surprised because they said, 'Oh I thought you would have a lot of friends,' but I had a few friends but they were too much, they had too much drama, so like… I always complain though, like when I got home, because I had nothing to do so I like wouldn't have anything to do on the weekends, so my friend would tell me we would hang out, and then like, we wouldn't end up hanging out. So, my mom was like 'College is coming, so… it'll change.'

Although Billy often reflected on the positive relationships he maintained with friends from his hometown, here, Billy added how he also experienced bullying, noting how his friend Kristen (his best friend from home) would come to his aid: "Because sometimes people would be

mean. They would just be mean. And Kristen said: 'Get away from Billy! Just get away from him!'" Here, Billy did not offer a possible explanation for why he thought he experienced bullying, but Johnny understood his ostracism as connected to his disability identity or, as he put it: "because I was in special ed a lot." Though Billy's sources of conflict were bullies, Johnny understood his participation in special education classes as the cause of his feelings of difference. Placement data show that students with IDD labels are among the most segregated in K-12 schooling, with only 16% being educated in inclusive settings (Kurth, Morningstar & Kozleski, 2014). Additionally, in most public schools, opportunities for reciprocal social relationships with their non-disabled peers are limited, with most students with IDD labels reporting friendships primarily with other students with IDD labels, or with family or paid staff (Biklen, 2005; Clement & Bigby, 2009; Cummins & Lau, 2003; Marquis & Jackson, 2000). For the students who participated in this study, they narrated understandings of their college friendships that paint a positive, though not uncomplicated, picture of this integral facet of college life.

As noted in the section above, the students documented and shared many photographs from social events or activities that were facilitated by AMP staff or traditionally-enrolled students who served as "peer partners" with the Student-2-Student program. The AMP students who participated in this study discussed the relationships they developed with the traditionally-enrolled students from Student-2-Student, characterizing these relationships differently. Booker had a picture on the home screen of his iPad of him and one of his peer partners, a cheerleader for CU. Additionally, Victoria's peer partner (also a cheerleader who specialized in baton twirling) helped secure floor seats for Victoria and another friend to watch a women's basketball game. Chris and Lawrence shared how they often went to the university gym with their peer partners. Jim explained to me how the Student-2-Student program worked: "So, Meg (EF: The

Director of the Center for Inclusive Higher Education) is the one that sets it all up. She has her

class, ED300, and at the beginning of the year she assigns students to go and see Carol (EF: one

of AMP's directors and the coordinator of the Student-2-Student program). And then Carol

decides who is matched up with who." Johnny and Jim reflected on their experiences with peer

partners from previous years, noting how they weren't always positive:

> Jim: It's pretty cool. I mean, they're (EF: the peer partners) technically supposed to ask
>
> you what you want to do, not *tell* you what you want to do… like, my freshman year I
>
> had a peer partner that just did whatever she wanted to do and didn't like ask me, so she
>
> got in trouble and like expelled from the program. We would watch like 'Is This Hot or
>
> Not' videos on YouTube. Or we'd watch videos about mixing different things with
>
> cereal… I don't know… with like hot sauce…?
>
> KV: Hmm. So yeah that was obviously something she wanted to do, and that you didn't
>
> want to do.
>
> Jim: Yeah.
>
> KV: How about you, Johnny, did you have a peer partner here?
>
> Johnny: Yeah but I didn't really like the one I had because we would just go back to her
>
> house and watch TV.
>
> KV: Oh ok.
>
> Johnny: I was like 'I don't really like doing that.'

The experiences that Jim and Johnny shared depicted relationships between college

students with and without disabilities that would not be considered authentic or reciprocal

friendships. Though this study did not collect data from the peer partners discussed above, Jim

and Johnny's story suggests that their peer partners were not interested in participating in the

Student-2-Student program to cultivate friendships. However, for many of the AMP students in this study, the Student-2-Student program represented a primary source of friendships.

Shannon, more than other students, shared pictures and anecdotes about her relationships with the traditionally-enrolled students who participated in the Student-2-Student program. As she described, she didn't think of those students as her "peer partners," but rather just considered them "friends," often blurring what she considered artificial distinctions: "I don't really have like, a Student-2-Student 'peer partner'… (stops herself) … well, I do… but they're just all my friends. Like Abby." In a later session, I learned that Abby took on a paid staff role for Shannon as a "peer mentor," supporting her academically to access one of her classes.

> Shannon: Karen, my friend Karen, like she was a peer partner to me, and like she went to Crane's Peak with us (EF: on an AMP-organized ski trip), and we do like a lot stuff together.
>
> KV: Oh ok. So, Shannon, you said that your peer partners, it's more like your friends. It's not really like an assigned thing?
>
> Shannon: Well, I mean it is, but I feel like it's more like friends, because like I got really close with… I guess.. well, Abby is not really my peer partner but like Reba is, but Lou (EF: One of AMP's directors) set me up with her. And we got really close. I mean I got close to everybody. Like, Kevin…. I mean… (stops herself…) well…he's not really a Student-2-Student person I guess.

Here, Shannon tried to describe the relationships she had with key individuals who she understood and her closest friends at CU, and had difficulty communicating who was a "friend," who was a "peer partner," and what it meant if someone, like Abby, or Kevin or Karen, were one and the same. Shannon exhibited an understanding of the challenge in calling someone who had

been "assigned" to her, a "friend." Because she considered their relationship to be close and authentic, she mischaracterized Kevin as "not really a Student-2-Student person," when in fact, he was one of the student leaders of the program who took on larger logistical responsibilities within the group (along with Reba). In a later focus group session, Shannon read a recent Facebook post she had shared on her page, reflecting on her first year at CU and referencing specific friends she had made. Aligning with the social media norms of "hash-tagging" as ways to call out specific people, Shannon included thirteen names at the end of her post. Two of the people she tagged—Jim and Booker—were other AMP students while the other eleven were traditionally-enrolled students who all participated in the Student-2-Student program:

> Shannon: I remember being so nervous on my first day of being a freshman at CU. Like I didn't really know anyone and I was scared that I wasn't going to meet anyone. I was shy too but now I talk a lot more than I did in the beginning of the year. I can't believe I am almost done with my freshman year I have met lot of great people being up at CU like I am glad I met u all we all became so close by just doing events like going apple picking, going to Evening Events, going to basketballs game and going to Reba house let's make rest of the semester great. #Jim, #Booker, #Reba, #Kevin, #Abby, #Chrissy, #Bethany, #Molly, #Linda, #Arianna, #Lucy, #Karen, #Yvonne.

Though I did not explicitly ask Shannon about why she elected to highlight her relationships with this particular group of people, I often observed her sticking close to specific students, mostly Reba, Karen or Abby, even as other AMP students tried to engage her in conversation. Shannon seemed to want to "pass" as a CU student, and often separated herself from the AMP program, or talked about her college experiences in ways that sought to erase any distinctions others would sometimes draw. In the section below about "Defining College," I

present an additional example of Shannon's understanding of herself as just another CU student, rather than a member of the AMP program.

While Shannon represented Reba and Kevin as "just my friends," Jim characterized their roles differently:

Jim: He's (EF: Kevin) not really a peer partner he's more of like a director and stuff…

KV: A director?

Jim: Like Reba. She's more of like a leader. Like, it's basically Reba and Kevin that like run the program (EF: Student-2-Student) with Carol and Michael and Lou and Meg (EF: Carol, Lou and Meg are AMP staff members. Michael is another AMP student who served in a leadership role in the Student-2-Student program.)

KV: But Reba and Kevin are CU students, right?

Jim: Yeah. I call Reba our "Den Mom" and Kevin our "Den Dad" (laughs). Because their personalities really are really associated with that, because Reba acts like a mother to us, and Kevin acts like a father to us.

KV: But they're college students…so it's not like they're older than you guys, or anything, right?

Jim: Right. But they look out for every single student.

While Shannon tried to erase distinctions between the traditionally-enrolled students and the AMP program students, here, Jim talks about Reba and Kevin in different terms, defining their relationship to the AMP students not as friends but as parents. Though it's typical for friend groups to have natural leaders—the friend who takes the impetus in making plans or the friend who always hosts get-togethers at his or her house—the findings from these data indicate that for students with IDD labels who attend college programs, their friendships with students without

IDD labels vary in character. While extensive scholarship exists about the friendship networks of young adults with intellectual and developmental disability labels (Kemp & Carter, 2002; Kolb & Hanley-Maxwell, 2003; Lutfiiyya, 1991; McVilly et. al, 2006; Siperstein et al., 1997; Ward et. al, 2013; Whitehouse et. al, 2001), few studies occur within the context of postsecondary education. Those that do reinforce this study's findings about the multi-dimensional nature of friendships for students with IDD labels. There exists ample extant scholarship that has found these relationships as ultimately mutually beneficial, however, most literature reports that the relationships between college students with and without intellectual disability labels are initially facilitated in some way by the structures and practices of the postsecondary education programs (O'Brien, 2009; Prohn 2014; Saarinen, 2016; Villemaire & Hallquist, 2013). In his study of social inclusion of students with intellectual disability labels in college, Prohn (2014) found that, similar to the students in this study, his participants viewed their peer partners as "social catalysts"—widening their social networks and facilitating their access to social events. Additionally, Prohn's (2014) participants were also aware of their program's role in organizing social activities. In a national survey of college students who participated in Best Buddies programming, Hardman and Clark (2006) found that individuals with and without disabilities reported benefitting from these relationships and that their lives were positively enhanced from participating in the program. Nicole Villemaire, a college student with an intellectual disability, identified her relationships with peer mentors as key in encouraging her to develop relationships with other classmates without disabilities who were not "peer partners" or "peer mentors" (Villemaire & Hallquist, 2013). The goal of this analysis was not to assess the authenticity or reciprocity of the friendships discussed throughout the focus group sessions, however, future research is warranted to investigate the mechanisms via which college students with IDD labels

make friends on campus and if and how those friendships are maintained outside the context of programs such as Student-2-Student. The next chapter will elaborate on this analysis and propose different ways to understand the friendship networks of college students with IDD labels.

Accessing Academics with Support

As noted in Chapter 3, during the first few focus group meetings I elected to provide some initial structure for the students by proposing a common theme around which to take pictures. Anticipating that student-reported college experiences would focus heavily on social activities and relationships, the first photo topic I proposed was "academic life." Since the students participating in this study represent a population that has historically been considered as antithetical to academic life (that is, higher education is, by definition, exclusive, and membership is determined based on traditional measures of intellectual ability or potential), I wanted to encourage conversations around accessing classes, interacting with professors, and navigating accommodations or other supports. The students in this study took classes ranging from yoga, Zumba, and self-defense, to music, cooking and nutrition, computer science, child and family studies, health and wellness and inclusive education. However, as my data showed, the students' narratives of their own academic experiences varied widely in terms of course selection and schedules, experiences with mentors, and perceptions surrounding access, participation and support.

As noted in Chapter 3, the AMP students had access to the entire course catalogue at CU and audited classes, rather than taking them for credit. They worked with the AMP program staff to choose their courses, often selecting courses with which AMP students experienced success in previous semesters. Since the students audited courses, they did not receive grades, as a few of the participants discuss below. All students had access to the same course material as

traditionally-enrolled students. Depending on the student and the class, the course material and requirements were sometimes modified to best fit student needs and strengths. While I did not collect data about if the participants in this study completed course requirements comparable to traditionally-enrolled students, those who I perceived as having more significant needs took courses that appeared to draw on competencies other than reading and writing. As I will discuss further in Chapter 5, three study participants were accompanied to the focus group sessions by outside support staff who worked with them at the university and in the community. These students, Victoria, Billy and Lawrence, were participants whose verbal communication access was uniquely complex. Though they navigated the focus group discussion space in strategic ways, this, along with the presence of paid support staff, signified to me that they were individuals with more significant support needs. Thus, their choice of classes drew on their interests and competencies that prioritized other intelligences beyond reading, writing and speaking. Victoria, for example, took a self-defense course and a yoga class, while Lawrence took a music appreciation course. The participants in this study had different schedules depending on their academic priorities, with some students taking one course from the CU catalogue and others taking two or three. Most students also participated in one program seminar from topics ranging from developing personal narratives to sexuality to job interviewing and resume writing. The seminars were developed and delivered by AMP staff and affiliated faculty, and though they were largely attended only by AMP students, the seminars were open to all CU students.

Most students in this study shared that they accessed their courses with the support of paid mentors who were hired and trained by The Epstein Center, a local disability service agency that collaborated with The Center for Inclusive Higher Education. As also reported by

Paeiwonsky (2011) and Prohn (2014), the students' experiences with their mentors varied. For example, Shannon went to her mentor for academic support with her child and family studies course, noting how she didn't often have an opportunity to interact with her professor:

> Shannon: It's a big class so we haven't really had any interaction, but she's nice so I guess she would be there, but I just go to my mentor if I need anything and be like 'Can you help me with this?'
>
> KV: And you said before your mentor was really great, right?
>
> Shannon: Well it's my friend Abby. And I knew her beforehand and so she had to be my mentor because there were no other mentors.

Shannon elaborated that because her professor set and maintained a fast pace of instruction, she relied on the support of her mentor to review her notes and prepare for exams:

> Shannon: She (the professor) goes way too like… (trails off….) …so, I don't really understand. I mean I do understand but it's just… that's why they go over it with me, my mentor. I get confused…But she (the professor) gave us like study questions like to review, like a review sheet online, but I'm confused what to study so I'm like, 'What?'
>
> KV: Is it because there's just lots of stuff on the review sheet… or…?
>
> Shannon: Yeah… I don't get it at all. I mean, I can ask.
>
> KV: How are you going to prepare?
>
> Shannon: I mean, I think I'll study. Well, I'll try to study with my mentor, Abby, like, I know she's busy but I'll try. We get to use notes on the test too.

Chris also mentioned how his mentor helped with note-taking for his cooking class, but added how he was familiar with the course content from his on-the-job experience working in the kitchen at the local zoo: "I mean, I know it's like basic stuff so I don't take notes on it. Well,

I don't take notes because my mentor takes notes. I mean, I listen, and I know what all that is. I know it all from the zoo. I learn it right from the zoo."

Jim reported a less-than-positive experience with one of his mentors, connecting his poor performance in a course with his perceived lack of mentor support:

Jim: I got out of my last classes. I kind of failed it anyway so I'm like 'what's the point of going to my last three classes?'

KV: Oh… uh oh...

Jim (sarcastically): Yep! I can thank the Epstein Center for it!

KV: What do you mean?

Jim: They gave me a mentor that didn't do crap. She didn't do anything. She never gave me her cell phone number, she never wanted to do homework, she didn't know anything about coding, she did her own stuff during class. And like she wouldn't go to the T.A. during class and be like 'Listen he's not doing well, can like, is there any way you can help him?' Nothing.

KV: Oh, that's too bad.

Jim (sarcastically): Yep! That's what I get for paying $20,000! And then she skipped a bunch of classes….so… (trails off).

In the section above, Jim shared his perspective about where to "locate" his challenges with accessing academics. He both cited his relationship with his mentor and what he understood as a failing of The Epstein Center to adequately train and match mentors with students. Without data about The Epstein Center's mentor training curriculum or data from Jim's mentor, it's difficult to determine the "accuracy" or "truth" of Jim's testimony. However, as other feminist-informed scholarship emphasizes, the project of this type of inquiry is not to look for one single "truth" or

approximation of "reality," but rather faithfully render the voices of informants to communicate their own experiences and characterize them thusly—to try to relay, as Haraway (1988) notes, "the view from a body, always a complex, contradictory, structuring and structured body, versus the view from above, from nowhere, from simplicity" (Haraway, 1988, p. 589). Relatedly, by assigning a $20,000 price tag to his AMP program tuition, which is approximately one-third of the advertised cost of one year at CU without considering any assistance from Medicare or SSI funds, Jim may be attempting to make a larger point about what he sees as a disconnect between expected value and actual value of his membership in the AMP program. Chapter 6 will extend this discussion about the participants' testimony and how both a feminist and Disability Studies-informed epistemological approach to study design and analysis offers new, alternative understandings about notions of "truth" and "accuracy" for informants with intellectual and developmental disability labels.

Despite his reportedly negative experience with his mentor, Jim added that he did enjoy his computer science course, but, as Shannon said above, the professor's fast pace made it challenging: "Well, I enjoyed the class. It was on coding and about how to make websites and stuff. It was a little challenging at first because when the professor finishes one thing he just flips to the next thing and it's like, 'Boom, here's the next part.' So, it's like…if you don't catch what he's doing right away you miss what you're doing."

Johnny also reflected on taking a difficult course but cited his own reading and writing challenges as the source of the difficulty:

Johnny: I also took Nutrition. That one was pretty hard. We talked about different stuff. Class was kind of hard, 'cause I don't read that well. So, if there was an assignment it was hard for me to do because my reading is… is not the best.

KV: Have you ever done books on tape, or listened to things?

Johnny: I haven't tried it. But it might help me. I'm better if I listen. Like I know what they're talking about if I listen. You could put your headphones in, and you can just listen. And you can focus. I want to try listening to a book, but I don't know how to do it.

In asking the students to reflect on what things might improve their academic experiences in terms of access or support, Johnny again raised the issue of audio supports:

Johnny: Or have, allowing them to have a recorder in class so like, if you're bad at taking notes you can just go back to your recorder and then listen to it and you know you what you have to do.

KV: Yeah, that's a really good idea. Is that something that you do in your classes?

Johnny: No, I should. Well like… no. I never tried doing it, but I should 'cause I'm more a good listener than writing. And I'm like, a terrible speller, so that would help.

Jim suggested securing notes, PowerPoints or other materials directly from the professor, while Jim, Johnny and Shannon highlighted their need for professors' time and attention:

Jim: Just getting on the same level as the student like, ask them 'what do they need?' kind of thing. Like instead of just saying 'oh I'm going to give you this this and that, kind of thing….' Like really asking them.

Johnny: Make sure they understand. Like make sure you know if they need help.

Shannon: Like, ask if I like need any help or anything. Like if you need help with homework or anything like that.

KV: Yeah, that's what Johnny said, to just kind of check in regularly…to see how it's going.

Shannon: I mean, my professor doesn't really do that this year, but I guess I haven't

really asked any questions… I mostly ask my mentor to help me with my homework.

Though all students in the AMP program were guaranteed accommodations based on their documented disabilities, they didn't explicitly mention if they availed themselves of these services. In fact, it was surprising to me that Johnny didn't mention having access to his course materials in audio format even though he communicated an awareness about his challenges with reading, or that Jim didn't discuss if he requested PPT access as an accommodation. Additionally, rather than go to her professor, or seek out university resources that traditionally-enrolled students access such as CU's Tutoring Center, Shannon appeared to depend on her mentor for notes, to clarify information and to prepare for exams. In Paeiwonsky's 2011 study of the college experiences of students with IDD labels, she identified similar themes regarding accessing academics. Notably, they echoed the tendency of students with IDD labels to rely on mentors, or what were called "educational coaches" on their campus, but cautioned that since "educational coaches can't help you with everything," students should instead "read the syllabus and ask for help if you need it," or "remember that you can go to Disability Services for help" (Paiewonsky 2011, p. 38). Daly-Cano, Vaccaro and Newman (2015) highlight the challenge that many students with disabilities face as they enter college and realize they are under-prepared to advocate for themselves and their support needs. During their K-12 educational careers, the Individuals with Disabilities Education Improvement Act (IDEIA, 2004) places the responsibility with schools to identify, assess and support students with qualifying disabilities and thus many students do not have opportunities to develop self-advocacy skills (Cano, Vaccaro & Newman, 2015). The protections and provisions of IDEIA do not extend into postsecondary education and thus Stodden et. al. (2003) found that many college students with disabilities do not have clear understandings of what their needs actually are, what rights and privileges they are

guaranteed under the Americans with Disabilities Act (1990), or how those rights undergird their college access. As will be discussed further in the next chapter, most participants in this study rarely alluded to their own disabilities, and few even used the term "disability" when talking about themselves, their lives and their experiences in college.

Defining College

Perhaps some of the most salient themes that emerged from analyzing the focus group discussion transcripts were how the students in this study defined college. The students articulated different understandings of what the Alma Mater Program was, and how their program fit in with the rest of Central University. They talked about how their experiences in college were different from those in high school, and reflected on how their own identities were thusly shaped.

Whether they described photographs that allowed them to reflect on academic experiences, social experiences, or their own identities as students, college represented a time of new beginnings (Ashby & Causton-Theoharis, 2009; O'Brien 2011; Paeiwonsky, 2011; Prohn, 2014). Additionally, even as the students reflected on academic experiences, these instances always bled into their social worlds. That is, both high school and college were never just about taking classes. Below, Jim compared his experiences in high school and college, noting how a course he took during the previous semester was a positive experience both academically and socially:

> Jim: School (EF: high school) wasn't always that great for me. Umm…like, I went to summer school twice. Now that I'm in college I'm doing a lot better and I'm doing a lot more. And last semester I took Meg's class (EF: AMP's director), and if she could give me a grade she'd give me an A-. And that was without a mentor. That was ED300. It's

like a Disability Studies class. It was really easy. I thought it was easy. It was fun. We

work with SCS too (EF: Special Community Services, a local disability service agency).

And they work on campus to allow students in Meg's class to hang out, do things with

them.

As noted previously, the directors of the AMP program worked with the students to select

courses that not only aligned with their interests, but that would be "good fits" in terms of

expectations, primary mode of instruction, and instructor willingness or perceived readiness to

welcome AMP program students into their classrooms. Thus, it's perhaps not surprising that Jim

described his experience in a Special Education/Disability Studies course (taught by the director

of The Center for Inclusive Higher Education) as overwhelming positive. Jim's knowledge of

disability services and supports was evident throughout the data collection period. He not only

took an active role in managing his own supports, he also worked with one of CU's disability

research institutes on projects relating to assistive technology and self-advocacy. Even though

Jim anticipated receiving an A- in this course, it's difficult to know how other faculty members

would evaluate students with IDD labels who access college courses via these alternative

pathway programs if they were fully matriculated. Knowing that the AMP students are not

earning degrees, but rather certificates, may affect how faculty members evaluate their

performance—what harm would it do to give an AMP student an A, knowing that it doesn't

carry credits with it? Additionally, assumptions about intellectual disability no doubt color

faculty members' expectations about student potential and student ability and begs the question:

if a student with a diagnosed intellectual disability produces "A" work, does he or she really

have an intellectual disability? Because the "zero reject" rule of IDEIA does not apply after K-12

schooling (students with disabilities are protected under the ADA, not IDEIA), the current

system of higher education is academically and, arguably, intellectually exclusive. The very nature of intellectual disability challenges if and how students with these labels can be regarded as authentic college students.

Johnny described how his experience in special education classes affected how he felt he was perceived by the rest of the high school community. He explained how he viewed college as different:

Johnny: I didn't really like high school, to tell you the truth.

KV: You said you didn't like high school?

Johnny: No. I think that they think if you're in special ed, they think that you're like, not the same as them. Like, I couldn't do anything more, like, because of my disability.

KV: Yeah… hmm. Did you feel different when you came to college?

Johnny: Yeah.

KV: Why do you think that is?

Johnny: Because you get a chance to like, do things.

Billy: A lot of things.

Johnny: You get a chance…you get support to like, do things that they wouldn't think you could do. And then you can prove them wrong. Like, you're a different person.

Johnny established a clear divide between himself and a theoretical "Them," who, presumably, represent individuals without disabilities whose deficit-based assumptions about intellectual disability contributed to some of his negative high school experiences. In characterizing college as a supportive place where he now had the potential to "prove them wrong," Johnny painted a picture of the special education system as definitively not supportive; a place where his potential was limited by others' low expectations. As Goode (1994) proposed,

Johnny's identity in high school was constructed and understood within that particular

institutional system—that is, Johnny came to view himself as he "existed-in-the-organization-of-

a-special-education-school" (p. 59). Consistent with findings from O'Brien (2009) and

Paeiwonsky (2011), Johnny saw college as a place to reinvent himself, to become a different

person than who he thought he was (or who others thought he was) in high school. In fact, in

Johnny's telling of his college experiences, the "Us vs. Them" divide seems to have vanished.

Billy reflected on how his parents also observed his evolution: "My mom is crying about me,

saying 'Oh my god, my boy is going to college….' I got my own life now. And my dad said,

'My boy!'" In *Think College's* short documentary, "Rethinking College" (2013) that profiles

students with IDD labels who attend postsecondary programs, Mary, a student at Kennesaw State

University, shared how, different from her experiences with high school teachers and peers, in

college "They [instructors and peers] accept you for who you are and they say, 'You're a college

student, you're a human being, you're the same thing here" (Think College, 2013).

    While some students did not make distinctions between AMP and the rest of the CU

student body, others drew specific boundaries around what defined AMP, thus communicating

different ideas about their own identities as AMP college students as compared with CU college

students. For example, in relaying an anecdote about chatting with a high school friend who also

wanted to attend CU, Shannon demonstrated an understanding of college in which she did not

make distinctions between AMP and the rest of CU:

> Shannon: My friend wanted to come here, and she used to miss school all the time and
>
> she wanted to come to CU and I was like 'I'm not sure you'd get into CU, because CU is
>
> a really hard school to get into.' I think she only wanted to come here because I was here.
>
> Community College didn't have my program, Child and Family Studies. We looked at

other colleges before coming here, and I'm glad I picked this one. I like CU. I think if I

went to like, CC, that… I dunno… I wouldn't like it as much.

Shannon defined her membership in college as academically selective, drawing a

distinction between CU's admission standards and those at the local community college. That is,

though AMP is a program specifically for students with IDD labels, Shannon viewed herself as a

member of the larger CU student body. Additionally, she explained her decision to come to CU

as a decision based on the availability of her chosen field of study. Shannon's identification as a

member of the CU student body overrode her association, in this case, with AMP as a distinct

program. As noted previously, all students in the AMP program need to carry a label of

intellectual disability to be granted admission, but Shannon felt so much a part of CU that here,

she didn't demonstrate an understanding of her own disability identity.

However, Jim, Chris, and Johnny exhibited different understandings of what their

membership in the Alma Mater Program meant. For example, Jim shared a conversation he had

with Shannon and one of their Student-2-Student peer partners about the AMP students not

receiving formal grades in their courses and receiving a certificate, rather than a diploma:

Jim: We definitely have a different identity. We had this conversation on Friday

actually—me, Shannon and Kim (S2S peer partner)—regarding identity. How it's not ok

how they do it with us… meaning, if we're doing the same work as everybody else then

we should get a grade like everybody else, not a pass or fail grade.

KV: So, that's how it works? You get a pass or fail grade?

Jim: Yeah. We don't get an actual diploma we just get a certificate that says that we have

graduated from the [non-matriculated students' college], or whatever.

As discussed in an earlier data excerpt, Jim viewed his participation in his academic

courses as comparable to traditionally-enrolled students. In their marketing materials, the AMP program reinforces Jim's point, noting that CU coursework is not modified, with AMP students having opportunities to fully access college classes. Additionally, in their short documentary about inclusive postsecondary education, *Think College* director Debra Hart notes that: "We're not talking about modifying curriculum or any course content. It's not bringing special education to higher education. It's about providing the supports and accommodations that will assist the student in being successful and participating in that class, and learning." (Think College, 2013).

Chris echoed Jim's sentiment, adding how since his membership in the AMP program meant he could only audit courses, he had decided to pursue community college classes that would earn him credits:

Chris: I have a meeting today at 1:00PM with the culinary people at [Community College] because I tried to get in here and they don't want me, so…because they said that if I'm at CC I'll really take the classes and I'll get grades in there, so I'll really be taking them.

KV: Did you think about taking culinary classes for credit here?

Chris: Yeah but they wouldn't let me so I'm going to do CC. That's why I'm going to CC. So I can take classes and get grades. I think it's boring.

KV: Boring?

Chris: Yeah, just auditing. I think it's boring. I mean, I want to learn to bake, so in the culinary class I'm taking at CC I had to cut like 200 tomatoes and 200 onions. They have their own bakery in the CC program.

Johnny articulated his understanding of the connection between earning a degree and getting a job, and noted how auditing classes in the AMP program might not offer that: "And it

doesn't add up to… like… a…regular… like a regular degree. Like to get like a good job. The same diploma to get the same benefits." Unlike previous scholarship where students with IDD labels cited their participation in postsecondary education programs as integral in securing post-school employment (Hart et. al. 2010; O'Brien 2009; Paeiwonsky, 2011), the excerpts above from Jim, Johnny and Chris express their ambivalence about AMP's ability to deliver on this promise. In Chapter 7 I will discuss these findings' implications and how they can inform future conversations about meaningful credentials in inclusive postsecondary education programs for students with IDD labels.

Towards the end of the focus group sessions that coincided with the end of their academic semesters, the students began to feel a bit wistful, often reflecting on everything that had happened in the past year. As included in the section above about friendships, Shannon shared one of her Facebook posts with the rest of the group, reflecting on how far she felt she had come during her first year at CU. After she shared, other students followed and reflected on their first days and weeks in the Alma Mater Program. Common themes emerged around initial fears that were quickly assuaged. Victoria noted how she "basically felt a little nervous…meeting new friends, that kind of thing," but that by enrolling in a cooking class, something with which she had experience, she then felt more comfortable: "I was actually happy taking that class. The hands-on cooking class. I wasn't really that nervous." Kerianne echoed this sentiment about initial nerves, adding that her first few days at CU were "tough with anxiety" specifically around "meeting different people" and "not knowing anybody" but that things were better now that "I have more friends. I know more people." Billy's friends from his hometown supported him in this big adjustment since, "I didn't know many people. But after that and coming to CU, I can just be Billy now." Jim was the most experienced student in the group,

having been enrolled in AMP for almost three years. His reflections about his first days and weeks at CU largely aligned with the rest of the group, though his made a distinction of how the program "used to be," before the Student-2-Student program assumed such an active role in event planning and organizing: "Just meeting new people at AMP was sort of difficult. We really didn't *do* much. As opposed to now we do anything and everything together."

The findings from these data show how the students drew clear connections between knowing people and having friends and their overall levels of satisfaction in the AMP program and at CU, aligning with findings across higher education literature that cite positive social relationships as inextricably linked to college student happiness (Freeman, Anderman & Jensen, 2010; Paul & Kelleher, 1995; Pittman & Richmond, 2010; Wilcox, Winn & Fyvie-Gauld, 2006). In fact, Wilcox, Winn & Fyvie-Gauld (2006) found that for their participants, developing a community of compatible friends was the most significant predictor of college student retention: "It was nothing to do with the university: it was just the people" (p. 707). Consistent with extant literature seeking to investigate the college experiences of students with IDD labels, the students in this study defined college as a time of new beginnings, different from high school, with opportunities for self-reinvention or self-actualization (Ashby & Causton-Theoharis, 2012; Neubert & Redd, 2008; O'Brien, 2009; Paiewonsky, 2011; Redd, 2004). Throughout the semester, Booker showed the group his social media postings where he shared dozens of selfies taken in front of locations across CU's campus—walking across the quad, in front of iconic CU buildings in which he had classes, next to the university chapel where he attended services, and in the library where he did homework and studied for exams. He developed a sort-of social media "refrain" that often accompanied these selfies, showcasing the pride he felt as a "dragon" in his new life as a college student. During one focus group session, he recited these hashtags:

"#RememberMyDragonLife, #CU2020, #CUNation, #LetsGetIt, #RememberMyName. Those are for me in my CU life. In my CU life I am happy."

This chapter discussed themes about the college experiences of students with intellectual and developmental disability labels. From focus group discussions organized around and supported by digital photos, the experiences of the AMP students in this study were characterized by frequent social events they attended with fellow AMP students and students who participated in the Student-2-Student program. Their college experiences were defined by challenging but enjoyable academics, as well as new friendships, facilitated by the Student-2-Student program. Additionally, the students in this study described how college was different from high school, providing new opportunities for self-discovery and self-reinvention. Lastly, the data in this chapter highlighted the students' different understandings of college, and what their participation in the AMP program meant for their post-school outcomes. Chapter 5 will discuss methodological findings about doing participatory research with participants with intellectual and developmental labels, while Chapters 6 and 7 will deepen the analysis and discuss the implications of these data, raising new and perhaps difficult questions for the field of inclusive postsecondary education.

Chapter 5

Methodological Findings

Chapter 5 addresses findings related to my third research question: What does inquiring into the experiences of college students with intellectual and developmental disability (IDD) labels teach us about doing research with individuals with IDD labels? This chapter includes methodological findings about developing and implementing a qualitative, participatory research project with college students with IDD labels. As noted in Chapter 2, qualitative research with individuals with IDD labels has been historically characterized as challenging. Previous scholarship that has sought to document the experiences and perspectives of this population cites challenges with communication, consent, and autonomy (Arscott, Dagnan, & Stenfert Kroese, 999; Beail & Williams, 2014; Booth & Booth, 1996; Clarke et. al, 2005; Harris, 2003; Jones & Stenfert Kroese, 2007; Lewis, 2004; McVilly et al., 2008; Nind, 2008, 2014; Scott et. al, 2006). Traditional avenues of "telling one's story" may not be sufficient for individuals for whom verbal speech is not reliable or meaningful, or for individuals who have been acculturated to align with dominant norms of performance and participation, such as individuals with IDD labels (Ashby, 2010; Biklen, 2005; Broderick & Kasa-Hendrickson, 2006; Cowley, 2012; Lester, 2015; Petersen, 2011; Wickenden, 2011). Thus, I designed this study with previous scholarship in mind, seeking to build upon participatory approaches to researching the college experiences of students with IDD labels (Paeiwonsky, 2011, 2014; Prohn, 2014). This study was as much about "the how" as it was "the what" and "the why." Therefore, this chapter shares methodological findings to illustrate "the how" in practice.

Organized into two sections, I discuss key findings about doing qualitative, participatory research with college students with IDD labels in relation to: 1) Collecting data in focus groups

and 2) The role of the researcher. In the first section about collecting data in focus groups, I present methodological findings about seemingly non-sequiturs: instances where students changed topics unexpectedly, interrupted each other, or took the discussion in new directions. Also in this section, I discuss the role of support across two contexts: 1) Between students and their support staff and 2) Among the students themselves. In the second section about the role of the researcher, I discuss findings about: 1) Researcher as teacher/authority figure, and 2) Flexible data collection decisions. This chapter concludes with a summary of its key findings and an introduction to the next chapter.

Collecting Data

As detailed in Chapter 3, this study employed a qualitative, participatory approach to describing and representing the college experiences of students with intellectual and developmental disability labels. Utilizing photographs as visual supports (Aldridge, 2007; Booth, 1996; Mathers, 2005) and ideas around which to organize discussions, the students who participated in this study met weekly in a focus group setting to share said photos and field questions and comments from the group. Previous scholarship has identified focus groups as a useful approach in researching the experiences of individuals with IDD labels due to their balance between structure and flexibility and opportunities for participants to build off one another (Barr, McConkey & McConagie, 2003; Fraser & Fraser, 2001; Ippoliti, Peppey & Depoy, 1994; Llewellyn, 2009). I did not analyze the photographs as data, but rather used them as visual supports that served to facilitate group discussions—the resulting transcripts and methodological memos comprised the data set that I then analyzed (Aldridge, 2007; Conder et. al, 2011; Noffke & Somekh, 2005). My decision to not analyze the students' photos myself was to center the students' own interpretations of their photos rather than my own. The findings in

this section highlight two methodological themes about collecting data in focus group settings with participants with intellectual and developmental disability labels: 1) Seemingly non-sequiturs and 2) The role of support.

Seemingly Non-Sequiturs

Early on in my data collection and concurrent analysis for this study, I noticed and began to code for instances where students shared information about themselves and their experiences that did not seem to fit with the flow of the focus group discussion. These interjections appeared so random that I labeled them "non-sequiturs" in my methodological memos and eventual coding. Since this methodological theme emerged as so central throughout the data (e.g. there were so many of them), I present characteristic examples of these non-sequiturs below. I eventually started calling these instances, "seemingly non-sequiturs" because my analysis suggested that what often appeared random and disjointed, could be understood as intentional or strategic by looking at these instances through a Disability Studies lens. The discussion that follows in Chapter 6 will propose alternative explanations for the function that these non-sequitur comments served, adding to or perhaps reframing the conversation about how to do qualitative research with individuals with IDD labels.

While all participants offered occasional non-sequitur comments, several participants did so more than others, confirming previously-documented trends in qualitative studies with individuals with IDD labels in which participants shared information at what might be inappropriate or unexpected times (Redley & Weinberg, 2007; Woodfield, 2016). Chris, Kerianne, Booker, Johnny and Victoria were the participants who most often contributed to group discussions in seemingly unrelated ways or at unexpected times. In the following excerpt, Shannon was sharing a picture of her outside one of CU's iconic buildings, noting how she really

liked that building and had asked a friend to take her picture in front of it. Chris interjected with a comment about his unicycle:

>Chris: So, next time I'll bring a video. I'll get video of my unicycle and show you guys.
>
>KV: Of your unicycle?
>
>Chris: Yeah. I could definitely unicycle on that (points to ledge on which Shannon is sitting in the picture.)

In the next excerpt, several members of the group were discussing music preferences, offering their favorite songs or genres. Kerianne did not share her thoughts about music, but rather told me about what she did over the weekend:

>Chris: I like 80s music. I like 60s, 70s and 80s music. I listen to all the classics. I like to listen to them at the zoo. Everyone at the zoo likes 80s music so that's what we listen to.
>
>Billy: Me too, but I like Hip Hop music.
>
>KV: Hip Hop?
>
>Billy: Yeah. Hip Hop music on my phone.
>
>Kerianne (to me): I went to my aunt's house this weekend. And then I went to my uncle's house.

During one focus group meeting, the students were reflecting on their initial impressions of life at CU and how they felt during their first days and weeks of the AMP program. Themes about defining college as a time of new beginnings were included in the previous chapter, though one illustrative instance of a seemingly non-sequitur warrants discussion here. As discussed in greater detail in the next section about the role of support, it was sometimes challenging for Victoria to participate in full group discussions. Her personality was a little more reserved compared to other students and thus, as noted in previous scholarship about qualitative methods

and individuals with IDD labels, the structure of a large group conversation was not always conducive to her participation (Booth & Booth, 1996; Clarke et. al, 2005; Nind, 2008; Woodfield, 2016). In a discussion about first days and weeks at CU, as Jim shared his initial confusion navigating campus, Victoria uncharacteristically interrupted him and began talking about a cooking class she took during her first semester, though the group had changed topics:

KV: Jim, when did you start here?

Jim: When did I start?? (laughs)…so this is 2017… so 2014. I started with Reba and Michael – the same year that they started.

KV: Were your first experiences living up to your expectations, or what did you think it was going to be like?

Jim: Umm. Difficult. Confusing. Because I knew the campus I just didn't really think about going to classes and stuff like that.

KV: And did it end up being as difficult or confusing as you thought it would be?

Jim (Quickly/sort of scoffing): Pssah. No.

KV: Oh wow, Ok. How so?

Jim: It was just confusing trying to get everything in line for mentors and stuff like that, and getting all the IDs and…

Victoria: (Interrupts Jim): I was actually happy taking that class. The hands-on cooking class. I wasn't really that nervous. It was confusing with new friends and stuff. But…. (Trails off…)

More than ten minutes before, it had been Victoria's turn to share her thoughts about what it was like during her first days and weeks with the AMP program. She shared her initial impressions about navigating campus, nerves about meeting new people, and becoming more

comfortable as time went on. However, here she interjected this seemingly non-sequitur comment about her cooking class even though the conversation had shifted to the experiences of another student. In this excerpt, Victoria answered a question that had been discussed ten minutes earlier, when the rest of the group had already moved on.

In our last focus group meeting of the semester, students discussed their plans for the next school year. Jim noted that he and Booker were thinking about living together in an off-campus apartment and shared some of their planning details. However, as included in the following excerpt, Booker took the conversation in an entirely new direction, sharing information about his upcoming birthday. Kerianne piggy-backed off this topic departure while Johnny changed the subject yet again. Kerianne closed the conversation by telling me about a surgery she had scheduled.

KV: So, is it just going to be you guys (Jim and Booker) in the apartment?

Jim: Yeah. Rent's not bad at all, it's like $475 a month, but the security deposit is $1500.

Booker (to me): Guess what I'm getting on my 24th birthday? [Unintelligible name] football jersey.

KV: Oh yeah?

Booker: I'm going to get it for my 24th birthday so I can wear it for the upcoming football season in the next fall. My birthday is July 25th.

Kerianne: Mine is soon. May 19th.

Booker: Oh, Happy May by the way (OC: The date is May 2.)

Johnny: I'm getting another tattoo.

KV: You are? What of?

Johnny: I don't know yet.

Kerianne (to me): I'm going into surgery.

KV: You are? Surgery for what?

Kerianne: On my ear.

Truth be told, I was often baffled by the frequency with which many of my participants offered these seemingly non-sequitur comments. My own commitments to interpreting disability in socially-constructed ways, or to assigning meaning or functionality to these instances were challenged as I often wrote memos that wrestled with these data. I felt tensions between believing that my participants' comments meant something and worrying how their communicative behavior would be perceived by others throughout the university community. I asked big, as-of-yet-unanswerable questions in my memos that documented these tensions: "What in the WORLD does this mean? How can these students authentically participate in class discussions? What can I do differently to structure discussions to keep the group on topic? Should I address these non-sequiturs or just move on? If they totally derail the conversation, does it matter?" While some scholars suggest that individuals with IDD labels' communicative or cognitive deficits may explain the cited challenges in participating in qualitative research, this dissertation's epistemological and theoretical approach to interpreting the data herein propose alternative explanations for what might be going on (Beail & Williams, 2014; Booth & Booth, 1996; Clarke et al., 2005; Goode, 1994). Lester (2015) also draws from "critical perspectives on communication" in her work with individuals with autism, purposefully privileging "non-normative ways of communicating" (p. 441) in efforts to uncover new understandings of speech that might typically be understood as nonsense, or without meaning (Biklen et. al, 2005; Biklen & Burke, 2006; Woodfield, 2016). Goode (1994) isolates the precise conflict I felt in wrestling with not only how to code these seemingly non-sequitur instances, but how to understand the

function they served for the students, and ultimately value them as purposeful. Describing his initial interactions with "Chris," a child who was deaf-blind, Goode (1994) notes, "I stopped trying to remedy the 'obvious' faults I perceived in Chris and tried instead to intuit, while interacting with her, what purposiveness or rationality her activities might have had from her perspective" (p. 30). The next chapter will discuss the methodological implications of these findings and propose new ways to understand the meaning behind these seemingly non-sequiturs.

The Role of Support

The role of support in these methodological data is multi-faceted and nuanced, looking different for each student and manifesting in sometimes unexpected ways. This section will present findings about the role of support in conducting this study in two different contexts: 1) Between students and support staff and, 2) Among students themselves.

Students and support staff. As with other students with IDD labels who attend postsecondary education programs, the students in my study and all those who accessed the AMP program had different and often unique-to-them constellations of support. Some students accessed support only for academics or other on-campus activities, being paired with a traditionally-enrolled student "mentor" who received training from the AMP program and The Epstein Center, an affiliated organization. Other students received support from local disability services agencies, hiring outside support staff members who accompanied them to not only university activities, but also supported them at home and in the community. These outside support staff members did not receive specific training from the AMP program and were not affiliated with it in any way. The students in my study who I read as having more significant needs, accessed college life with the support from outside paid support staff unaffiliated with

AMP, often the same individual, who transported and accompanied them to classes and social events (Hart et. al, 2010; Neubert & Redd, 2008; O'Brien, 2009; Paeiwonsky, 2011; Prohn, 2014; Redd, 2004). It was important for me to allow the students with support staff to decide if and how they wanted said staff to participate in our focus group meetings. Thus, for the first few meetings, Lawrence, Victoria and Billy (three students out of the group of ten) had support staff present. Joseph, who, as noted in Chapter 3, only attended sporadic focus group sessions, was always accompanied by Linda, a support staff person. Upon arriving (typically a few minutes late), Linda frequently popped her head in the door and apologized to me for Joseph's tardiness. On one characteristic instance, Linda apologized profusely: "I'm so sorry I'm bringing him late! We were heading over from his class at the Johnson School building and we were trying to hurry! I'm so sorry he's late!" I was often turned-off by Linda's apologies because they communicated to me that she saw herself as somehow responsible for Joseph's schedule, when in fact he was a non-traditional student in his late 40s who, as far as I was concerned, could decide if he felt it necessary to apologize for arriving somewhere late. Previous research about the dynamics between support staff and adults with IDD labels supports my interpretation of Linda's behavior, documenting the limited opportunities for independence and autonomy, specifically with regards to transportation and use of time (Abbott & McConkey, 2006; Randt, 2011). Before entering the focus group meeting space on the first day, the support staff—Amy, Irene and Holly— approached me to ask if it was ok that they stayed. In keeping with the study's design to align with Disability Studies values of self-determination and consultation, I redirected the questions to the students themselves, who all agreed to their presence, though it was unclear at the time if their presence was preferred, or just accepted. That is, the three students with support staff members didn't necessarily express strong desires for the presence of their staff, it

was just assumed they would stay (Llewellyn, 2009). In the final chapter of this dissertation I

discuss limitations connected to support staff presence in research encounters and inclusive

postsecondary education programs broadly and propose how future scholarship and practice

might navigate these concerns. As tends to happen in classroom spaces or in other group meeting

scenarios, each person found "their seat" and didn't often stray from those same seats throughout

the semester. Likewise, the support staff members chose their respective locations: Irene chose a

seat set back from the table in the corner behind Lawrence, while Holly and Amy sat at the table

next to Victoria and Billy. As unfolded throughout the focus group sessions where they were

present, the support staff members' seating choices reflected how they approached supporting

the students with whom they worked. Holly and Amy most often inserted their own ideas and

commentary in the students' discussions, while Irene's presence remained auxiliary, supporting

Lawrence when she felt it was necessary or he looked to her for assistance, but otherwise

remaining on the periphery. Below I expand on the relationship and history that Victoria and

Holly shared outside the context of the research study and how their shared history may have

affected what happened in the focus group space. Additionally, the final chapter discusses

recommendations for inclusive postsecondary programs with regards to support staff training and

role-definition.

As noted above, the students who were accompanied by outside support staff members

were those who I read as having more significant needs (Billy, Lawrence and Victoria),

specifically with regards to verbal communication and literacy skills. Thus, the role that support

staff members adopted in supporting the students' participation was to repeat or confirm the

statements the students made, or to ask the students a series of questions to structure their

participation in group discussions (Llewellyn, 2009). Billy's outgoing, charismatic personality

meant that his participation in focus group sessions was frequent and animated. However, his speech was very difficult to understand for individuals unfamiliar with his communication style and structure. Throughout the sessions she attended, there were frequent instances of Amy (Billy's support staff person) repeating back a comment of Billy's verbatim, or, repeating his statement in the form of a question to clarify his meaning and facilitate his participation (Conder et. al, 2011; Llewellyn, 2009; Ramcharan et. al, 2004). As I became more adept at understanding Billy's communication, I often did the same thing, attempting to confirm my own understanding of his meaning. However, even in the instances where Billy's speech was completely intelligible, this repetition continued. For example, when Billy talked about attending a movie night at Reba's house (one of the Student-to-Student peer leaders), Amy repeated what he said:

> Billy: Yeah then I went to Reba's house too.
>
> Amy: You went to Reba's house?
>
> Billy: Yeah. Movie *Finding Dory*.
>
> Amy: You watched *Finding Dory*, right?
>
> Billy: Yeah.
>
> Amy (turning to me): They had an event at like a home theater, it was (pauses)… I think it was February 20th, where they all watched *Finding Dory*.

What I found so striking about this interaction was how, even though this was an instance where Billy's speech was intelligible, Amy still repeated what he said. Though subtle, and in a way that seemed to serve as their short-hand, Amy edited Billy's contribution into what most would consider "correct" English—from "Movie *Finding Dory*" to "You watched *Finding Dory*, right?" Even though the meaning of Billy's offering was clear, ableist norms of communication, performance, and competence informed Amy's decision (likely a subconscious one) to ultimately

cleanse and repackage Billy's speech into a format that she deemed correct (Biklen & Atfield, 2005; Milner & Frawley, 2018; Woodfield, 2016). Chapter 6 takes up and extends this finding, discussing how qualitative researchers can recognize and build on opportunities to construct communicative competence for participants with intellectual disability labels that may manifest in complex communication needs.

In another excerpt, Billy described the photo he decided to share with the group—a selfie of him and friend at a university basketball game, wearing clothing with university colors and insignia. The transcript showed how Amy repeated Billy's words back:

KV: Billy did you take that photo? Was that a selfie?

Billy: Yeah, I did. My friend Kristen, she's going to come visit me soon. Here.

Amy: Oh, she's going to come visit you here? That's cool. Is she still in high school?

Billy: Yeah.

Amy: Which high school?

Billy: Monrovia.

Amy: Monrovia? OK. She doesn't look like she's still in high school she looks older.

Billy: Yeah, she's going to be a senior.

Amy: She's going to be a senior? Ok.

Though this study did not undertake a discourse analysis of the data, the convention of repeating back words or phrases seemed to imply that both the staff members and I did not initially trust Billy's contributions, or did not trust our own comprehension of them. Though subtle, and certainly not done with ill-intent, this practice may have served to discount Billy's or other students' participation in group discussions, reinforcing dominant ideas about individuals with IDD labels exhibiting difficulties with group discussions (Booth & Booth, 1996; Clarke et.

al, 2005; Nind, 2008; Woodfield, 2016). Alternatively, this convention could have been a strategy that Amy developed to ensure that Billy was "heard" and understood, as a way to facilitate not only his access to group settings but facilitate others' access to Billy to ensure that others were able to benefit from his presence, his ideas and his sense of humor. Goodley (1997) suggests that staff can assume many and often shifting roles in their efforts to support people with disabilities in self-advocacy and research settings—their "interventions" aligning with either a "professionalizing" (acting like staff) approach to support, or a "bolstering" one (acting together) (p. 441). Without additional data that focused on the dynamics between staff and students, it's difficult to draw firm conclusions about the nature and character of these relationships, but these findings invite closer investigation.

Alternatively, Irene's approach to supporting Lawrence's participation in the focus group sessions was to ask him a series of questions that, when answered, explained his rationale for whatever photo he elected to share (Conder et. al, 2011; Ramcharan et. al, 2004). In the instance below, Lawrence shared a selfie of him smiling directly into the camera. He was wearing a striped shirt with a "volunteer" sticker on the front and had a lanyard around his neck:

Irene: Hey Lawrence – who's that? (Silence.) Who is this?

Booker: It's Lawrence, he looks smiley.

KV: The King of Selfies. Where are you?

(Lawrence doesn't immediately respond.)

Irene: See that "volunteer" sticker?

Lawrence: 603 (EF: "603" is a second-hand clothing store on CU's campus).

KV: What are you doing there? What does your sticker say?

Lawrence: The sticker say, "Lawrence Smith: Volunteer.

KV: Ok, do you go there every week?

Lawrence: Yeah.

KV: What days?

Lawrence: Saturday, Sunday…

Irene (Stops him and corrects): No no, when are you at the 603 store?

Lawrence: Tuesday and Thursday.

KV: What do you do there?

Lawrence: Do there? Campus Plaza Mall (EF: Where the 603 store is located.)

Irene: In Campus Plaza Mall, yes, but what do you do when you're there? What kind of

work do you do?

Lawrence: Uhhh, fold clothes…

Irene: What does Curtis (the store manager) give you when you walk in? To hold?

Lawrence: The keys. The keys. I hold the keys.

Irene: Keys for what?

Lawrence: Keys for the dressing room.

Contrasting with Amy's approach of repeating Billy's words back to the entire group, in the

excerpt above, Irene attempted to set up Lawrence for communicative success by providing him

with context, with subtle reminders, or with specific questions that allowed him to participate in

the group activity of photo-sharing.

As noted at the beginning of this section, the students in the AMP program utilized

different kinds of support to participate in not only the university but at their homes and in their

communities. Holly's relationship with Victoria was particularly close, since Holly supported

Victoria in all aspects of life beyond the AMP program. Additionally, Holly was not trained by

AMP program staff, but rather worked for an outside disability service agency. Perhaps more than the other support staff, Holly assumed an active and almost central role in the discussion during the sessions she attended with Victoria (Llewellyn, 2009). When a question was asked of Victoria or it was her turn to share a photo she had taken during the previous week, Holly would often jump in and speak for Victoria or ask questions on her behalf. In the first focus group meeting where the students began sharing their photos, Holly spoke for Victoria and asked my permission to share specific ones: "Is it ok that Victoria does three because she has three that she really wants to share? One is of her and the women's basketball team, one is of her and her peer partner, and one is of a class that she was participating in." Later in that meeting, I asked if everyone had sent along a picture for me to project on a screen for the group to see, and Holly offered: "I sent Victoria's… we take lots of pictures, don't we, Vic? We take tons of pictures." In the discussion that followed about Victoria's selected pictures, Holly supported Victoria to explain the first one, showing Victoria in a boxing stance, punching the padded hands of an instructor:

    Holly: Vicky, who is that?

    Victoria: Me doing self-defense.

    KV: Wow, neat. So, Vicky, where was this picture taken?

    (Wait time.)

    KV: Was this at your home? Or was this at the gym…?

    Vicky: This was at the gym.

    KV: Oh ok.

    Holly: Do you remember what gym we were at?

    Vicky: Umm...

Holly: It starts with an E...

Vicky: Emerson.

KV: Ok great, so the student gym. So… (looking at picture...) you're not punching a person, are you?

(Billy laughs, a few others laugh)

Vicky: Uhh no… I am not punching a person.

Holly (laughs): I had to capture the first punch!

Vicky: Yeah, you had to capture the first punch.

Holly (turning to me): She could hardly make a fist, she doesn't have a mean bone in her body!

KV: And was this a class that you took?

Vicky: Yeah, a class. It was self-defense.

KV: So, they taught you how to punch someone?

(Can't hear Vicky over the other conversations going on.)

KV (trying to refocus): Does anyone have a question or comment about Vicky's picture?

(Silence.)

Holly: Do you remember what the officers taught you?

Vicky: Ummm the officers… hmm… they taught me… (trails off).

Holly: In... the self-defense?

Vicky: What did the officers taught me? They helped me learn different techniques.

In the excerpt above, Holly asked Victoria questions to facilitate her participation in the picture-sharing discussion. For the next photo, however, Holly included a lot of her own commentary, and Victoria did not have as much of an opportunity to contribute her own thoughts

(Carey, 1994; Llewellyn, 2009; Lord & McKillop-Farlow, 1990). Victoria shared a picture of her posing and smiling for the camera with ten to twelve members of CU's women's basketball team. Rather than hearing from Victoria, it was Holly who explained the events surrounding this picture:

> Holly: So they came… it was like, her highlight of her night… She didn't know that it was going to happen… me and Kristen (EF: Vicky's peer partner) were kind of stirring this up, and her friend in the picture, we saw him walking past, and we had floor seats, so he came over and sat with us. We had two seats next to us, so we kind of included Caleb into it which was pretty fun.
>
> KV (to Victoria): How did you get floor seats?
>
> Holly: But she didn't KNOW! How did we get floor seats, Vic?
>
> Vicky: Umm basically, they basically had…
>
> Holly (interrupts): Do you remember how we got floor seats?
>
> Vicky: Umm, tickets?
>
> KV (to Victoria): How'd you get those tickets?
>
> Vicky: Umm we had to pay for them at the front desk.
>
> Holly (Giggles and looks at me): Well, Kristen had asked if we could sit down there and watch her perform (EF: Vicky's peer partner Kristen is a cheerleader), so we got to sit close. And then we had surprised Vicky with being able to see the team. So, one of the players, I have a picture of one of the players who had asked to take a picture with Vicky, and Caleb (EF: Vicky's friend from home). And the team, we were standing around just hanging out and then the next thing you know, the team just comes out going, "Vicky! Vicky!" and they know her name, and it was pretty cool… And the coach came right on

out.

KV: And so, Vicky, you didn't know that was going to happen, it was a surprise?

Vicky: Yeah, I didn't know it was going to happen… I was like 'Whoa.'

Holly (to me): They asked her a couple questions, to get to know who she was…and it was like, a good half-hour, 45 minutes, we were standing on the court and they were just like, wanting to talk to Vicky…I mean, they were just…They invited Vicky to go practice with them, which was pretty cool, so when they come back from, you know, the tournament, she can go and practice with them!

Both Holly and Amy, the support staff, often characterized Victoria and Billy's experiences as a "we"—integrating themselves into the experiences of the students. In Holly and Amy's case, they were hired and trained by an outside disability service agency, rather than the AMP program. For example, to communicate that Victoria enjoyed taking pictures, Holly stated: "We take a lot of pictures, don't we Vic?" When it was time to leave for Victoria's next class, Holly often communicated that as a "we" as well, as she did on one day by saying: "We gotta go to class. [Prompts Victoria] *Say*: "See you later, Billy!" Additionally, in determining if the students planned to participate in an upcoming community event, Holly and Amy shared information about the students' schedules as follows:

Holly: Are you guys going to National Down Syndrome Day at the mall?

Amy: Yeah, I think so.

Holly: Ok, Vicky and I are going to be there.

Amy (to Holly): What day of the week is it?

Holly: Tuesday

Amy: Yeah, I think we can do that.

Towards the end of this session, Holly suggested a lunch location to Victoria, sharing an anecdote about their restaurant preferences. In the excerpt below, Holly noted a switch from eating at Taco Bell to eating at Moe's, though from her use of "we," it's unclear if Holly is sharing information about her own experience with Taco Bell or Victoria's experience with Taco Bell:

Holly: Vic, you want Moe's for lunch today?

Victoria: Oh yeah.

(Holly and Amy talk about where they're going for lunch. Amy mentions "Taco Tuesday.")

Holly: No, we can't eat any more Taco Bell, can we Vic? We ate so much Taco Bell when they came out with those…those spicy meat ones, we were eating three at a time.

Irene, the support staff person who worked with Lawrence, also framed Lawrence's activities as "we," noting that during the university's spring break week, Lawrence still planned to do his volunteer hours at the 603 consignment store: "We still show up whether or not there's class, because we volunteer at the 603 store."

Physical manifestations of this "we" also arose for Amy and Holly, the support people who worked with Billy and Victoria. During one focus group session, Billy was unable to access his App store account because Amy's email address and password was attached to it, meaning that Billy was unable to download the "Pic Collage" app the other students were using to create digital photo collages. During one focus group session, Victoria was unable to locate her phone to share her weekly pictures with the group. I asked her if she had her phone with her that day and Victoria replied:

Victoria: Umm... do I have my phone with me…?

KV (looking around Victoria's seat area): Is that your backpack or is that Shannon's

Shannon: That's mine.

KV: OK, hmm, where might Vicky's phone be…?

Victoria: It might be with Holly.

KV: Ok, maybe Holly has your phone, let me go check with her.

In the memo I wrote after this focus group session, I had noted that Holly, Victoria's support person, was sitting outside the meeting room with Victoria's coat and backpack, with Victoria's cell phone inside the backpack. As seen in previous scholarship about the roles of support staff in the lives of individuals with IDD labels, Holly often assumed more of a "care" role, rather than a "support" or "advocacy" role (Abbott & McConkey, 2006; Alaszewski et. al, 1999; Llewellyn, 2009; Oliver & Barnes, 1998; Randt, 2011). Once Victoria had possession of her own belongings, she tried to locate the pictures she had taken the previous week and was unable to find any pertaining to the topic at hand. Holly was not present during that focus group meeting (because of the methodological decision to not have support people present that I will discuss in greater detail), but popped her head in towards the end, noting that she had Victoria's on-topic photos in her cell phone before saying to me (again using "we"/"our"): "We have to leave for class now. What's our homework for next week?"

For Victoria, Billy, and Lawrence who utilized support staff to access the AMP program, the data showed that their participation in this study looked different than the participation of the students who did not have support staff. Literature about the role of support persons in the lives of individuals with disabilities is characterized by debates around physical proximity, if the support is relevant or useful, and its overall function (Giangreco et al., 1997; Malmgren & Causton-Theoharis, 2006; Rossetti, 2012). Previous scholarship suggests that, unsurprisingly, the

language choices and subsequent actions of staff members who support people with disabilities in research settings reflect their own philosophies about disability and thus manifest in the support they provide (Goodley, 1998; Llewellyn, 2009). Beyond simply evidencing personal views about disability, Llewellyn (2009) found that the behavior of staff in supporting individuals with disabilities to participate in focus group research was also largely influenced by the ruling ethos of the larger institutions of which they were a part. Holly, Amy, and Irene were hired and trained by local disability service agencies, not the AMP program, therefore their attitudes about disability and how their support manifested, likely reflected both their own personal philosophies and the philosophies that informed their employers'. Thus, the final chapters will discuss thematic and methodological implications of these findings and propose new questions for future scholarship.

Among students themselves. Throughout the focus group sessions, findings around the role of support demonstrated how students supported one another to participate in the discussions and picture-taking activities (Cambridge & McCarthy, 2000; Farquahar & Das, 1999). The students supported one another in various ways from accessing and trouble-shooting their own technology to supporting each other's participation in group discussions. Several students struggled with remembering their passwords, logging into email accounts, or navigating various picture-taking apps or programs. While initially Victoria, Billy, and Johnny received help from support staff to take and share photos with the group, they eventually drew on the support from peers (particularly Shannon and Jim) to participate in these same activities. In discussing who was going to attend an AMP outing to a local hockey game, Johnny was unable to locate the email that contained the relevant event details. Jim guided him through the steps to try to find it: "Johnny, if you log into your email, go in here and go into your Inbox and search for 'Carol'

[one of the AMP directors] or search for 'Student-2-Student' and you'll find it." Though these

instances occurred naturally throughout the semester, I made a methodological choice to create

and foster these peer support opportunities. After observing their facility with technology

generally and photography apps specifically, I asked Jim and Shannon if they would teach the

group how to make digital collages of online photos. In the excerpt below, Jim and Shannon

discussed an app called "Pic Collage," and shared with the rest of the group how to use it:

> Jim: Yeah, I mean you can use different programs, I just don't really remember how I did
>
> it…
>
> Shannon: Well I have Pic Collage. It's like an app on the phone.
>
> KV: Oh, ok so there's an app for it. So, it's not connected to Facebook, it's connected to
>
> your phone?
>
> Jim: Right. Well, you can do it on a phone, on a tablet, you can do it on a PC…
>
> Shannon: This is what it looks like (shows me the app on her phone) you can do a bunch
>
> of different ones.
>
> KV: Cool. Pic Collage. I'm going to write that down. So, then you just pull photos from
>
> your photo library?
>
> Shannon: Yeah. I'll show you. (Gets out and shows me how to access app and select
>
> photos.) So, I made a bunch of collages. Like this one I made from a while ago (shows
>
> the group).
>
> KV: I wonder if you can get this app on your computer as well as on your phone…
>
> Jim: Yep you can.
>
> Johnny: I wonder if you can get it on your iPad?
>
> Jim: Yep you can. On the Mac… Mac…computer.

Johnny: You mean Apple?

Jim: Yeah, you can get it.

KV: Ok, I'm going to try to find this app in the App store.

Shannon described how to go about creating a collage utilizing various platforms while Jim demonstrated an example:

Shannon: So, if you open the app you can pull photos from like Facebook and everything… like, these are all the photos I have from CU so I can pick from here. Your photos can connect to your phone and you can get photos from Facebook too, if you say that like you want it (the app) to connect to Facebook.

KV: Cool, and then you pick whichever ones you want, and then it creates a collage?

Jim: So, like with mine, you can do a collage or you can do like four-in-one.

KV: Right like Lawrence did.

Jim: You can do templates online – so I'll do an example.

Booker, Billy and Johnny got out their devices to try to access the App store and download Pic College so they could follow along with the rest of the group. However, in this and other instances throughout the data collection period, they all had trouble logging into the devices themselves or accessing their App store accounts. Here, when Jim went over to help, he realized that Booker had configured his iPad to Touch-ID, asking him: "Well, which finger did you use to set it up?" Booker became frustrated because he wasn't sure he was the one to set up his device in the first place. Johnny could not remember his password so Jim helped him navigate through the prompts to reset it. Johnny did not know the login information for his university email account and noted he would have to check in with Lou (an AMP program director) to figure this out for next time. Likewise, upon trying to find and download the Pic

Collage app, Billy realized that his iTunes account was connected to his support staff's email address, and he did not know her password. These data confirm findings from previous scholarship that discusses individuals with IDD labels and their reliance on support from staff or family (Abbott & McConkey, 2006; Randt, 2011). Additionally, these findings concur with research that identifies inadequate access to assistive technology as disempowering for individuals with IDD labels, specifically with regards to education access, socioeconomic status and developing and maintaining interpersonal relationships (Owuor et. al, 2017; Walsh et. al, 2017). Learning that Booker did not set up his own iPad or that Billy's App store account was connected to his staff person's email rather than his own, highlights the need for postsecondary education programs to emphasize the development of self-determination and self-advocacy skills, in hopes of encouraging students to assume responsibility for their own technology and foster greater independence (Owuor et. al., 2017, 2018).

However, some students found ways to navigate around their technological access challenges to still participate in the photo-sharing discussions. Though they were not always on topic, Victoria and Johnny often constructed their own participation. For example, when Victoria realized that she did not have the on-topic photos saved on her phone (as explained in the previous section), she offered: "Let's see…(Looking through pictures on phone)… I wonder if I can find a picture that I want to show… let's see. I can share a picture of my friends?" Knowing that he was unable to connect to the university Wi-Fi because he did not know his password, Johnny proposed: "Can I just show you my picture on here? (Holding up his iPad to show me)… because I don't have Wi-Fi to send it to you?" While deficit-based assumptions about individuals with IDD labels that depict them an unable to maintain ownership of their personal property served to create situations where both Victoria and Johnny were unprepared to fully access the

group activity, their ingenuity and ability to work around these obstacles provided a counter-narrative that showed them as creative and resourceful actors (Woodfield, 2016).

The students developed a dynamic within the focus group in which, though it often ebbed and flowed, they piggy-backed off each other to represent and contextualize their college experiences (Cambridge & McCarthy, 2000; Carey, 1994; Farquahar & Das, 1999; Fraser & Fraser, 2001; Llewellyn, 2009). This dynamic acted as a natural support on which the entire group could draw to encourage new discussion directions and uncover previously-unearthed insights about the representation and meaning of their experiences in AMP. The theme of students supporting one another to participate in group discussions arose early in the study. For example, in our second focus group meeting, I facilitated a discussion about the meaning of "research" to gauge the students' previous knowledge and introduce their photo-taking and sharing activities as a form of research. In the excerpt that follows, the students offer ideas, building the group's understanding from person-to-person and demonstrating their knowledge of research:

KV: So, does anyone know what it means to "do research"?

Jim: To do a study?

KV: Yeah. (Writes on board) To do a study about what? For example?

Jim: About anything.

KV: Yeah, you're right, it can be about anything. So, what's an example of a study that you might do research about?

Jim: Drug study! (Group laughs)

Booker: Drug study??

KV: You mean like medicine?

Jim: Yeah yeah, like medicine – not like hard drugs, Booker!

Booker: Oh oh! (Group laughs again)

KV: Yeah that's true. OK, ummm so… anyone else know anything about research?

Jim (continues): Yeah, like where I work we do a study about like… what kind of technology people use.

KV: Ah ha, yes. So, "use of technology." (Writes on board)

Shannon: You could do a study of like medicine… like, you could do a study of like medicine of when you're sick.

KV: Yeah exactly.

Johnny: Like curing a disease. Like curing cancer or something.

KV: Right, you could do a study about curing a disease, about all sorts of things.

Booker: Can you do research to study, like, science fiction?

KV: Yeah, absolutely (writes on board) – so tell me a little bit more about that.

(Booker is quiet… someone else offers: "Like UFOs?")

KV: Is that what you meant Booker?

Booker: Yeah, like if they're real or not real.

KV: Yeah, so a study that tries to prove the existence of UFOs. Right.

Booker: Yeah like it's that E.T…. I forgot what it stands for…

KV: Extra Terrestrial.

Booker: That one!

Johnny: You could do research about like animals… about like endangered species.

KV: (Sounds surprised and impressed): Yeah! Great one. You could do research about endangered species. (Writes it on board)

Booker (As an aside): I heard they're pretty dangerous too.

KV: So right (addressing Booker's point) there could be animals that are dangerous like lions or tigers, or there could be animals that are "endangered" like Johnny said. Johnny, could you explain a little bit about what "endangered" means?

Johnny: Like… less of that animal around.

KV: Yeah, absolutely. So if, for whatever reason, animals' natural habitats are going away – let's say humans are moving in –

(Someone say something about dinosaurs and Booker says as an aside: "They're all dead already.")

Chris: Like bald eagles.

In the excerpt above, almost all the students present during this early focus group meeting contributed to the group conversation, each offering a piece of information about what research meant and creating a group understanding of that concept. The discussion continued and the group generated ideas about researching bald eagles and how to collect data about them:

KV: Right! Like bald eagles. So, you might want to do research about, let's say, how many bald eagles are left in the country. So, let's say there's a study to try and count the number of bald eagles left in the country, how would you go about doing that? What would you need to do to figure that out?

Johnny: Well you would…you know how certain animals have like, numbers on them?

KV: Yeah! Like to tag them!

Johnny: Yeah, like to tag them and then to track them.

KV: Yeah! Absolutely. So, if you were studying bald eagles, what other ways might you collect information about them?

Jim: Like the color?

KV: Yep, the color. So, what they look like. So, the color, the size….

Jim: The shape?

KV: Yep, the shape. Gathering data about how much they weigh, how big they grow….

What are other ways that you might be able to get information about bald eagles…what

might you want to do?

(OC: There is a longer pause here and, perhaps because of the longer pause, Joseph

jumps in.)

Joseph: The web… the internet?

KV: Yeah! Exactly! So, you might want to do some background research. So, what kinds

of information would you want to look up, or Google, Joseph?

Joseph: I don't know.

KV: Ok, so for example, you might want to find out about where they live?

Joseph (picks it up one second later): Where they live, what they eat…

KV: Right! So, let's say you figure out that most bald eagles live out west in Montana,

for example, and you decide you're going to go to Montana in order to observe them.

What kinds of things might you do?

Shannon: (Begins to say something and stops herself.)

Jim: Go bird-watching?

KV: Right! Ok, Shannon, what were you going to say?

Shannon: I was going to say… (trails off)… I forget…

KV: Ok, well let's see, Jim said bird-watching, what kinds of things would you need to

do that?

Jim: Binoculars or a camera.

By the end of this conversation, the students established a common understanding of what research was and proposed ideas about how to design a study about bald eagles and collect photographic data about them. While the topic of conversation—doing research—was not the primary takeaway from this data excerpt, the key finding for me was about the group's process. The students acted as natural supports for one another, scaffolding each other's contributions to the discussion and fostering a shared understanding about research. Often, my post-focus group memos would include questions or observations that showcased my surprise or sometimes, frustration, that the students who participated in this study carried labels that I considered unreflective of their abilities or potential. I had many conversations with colleagues in which I often wondered why my participants chose to attend an alternative pathway college program where they earn a non-credit-bearing certificate, rather than a community college where they could earn a degree? The memo I wrote after this first session included musings about some weighty concepts that I will further unpack in the next chapter, including: "Will transcribe and do some more expanded field notes later, but my overall takeaway is: WOW! This is a smart group! How they heck did they end up in this program?"

Throughout the semester, the students continued to support one another to participate in group conversations and represent their college experiences, further evidencing this theme of in-group support processes at work. Sharing photos about their academic lives in the AMP program, Kerianne took a picture of the front of the textbook for her Health and Wellness course. When I asked her about what she learned in that course, Kerianne experienced some difficulty describing the course content:

Kerianne: I am taking Health and Wellness this semester.

KV: Oh, a health and wellness class. OK. What kinds of things do you do in there? In the class?

Kerianne: Like… (pauses)… go through books. And papers.

However, in describing and answering questions about Kerianne's picture, the students worked through ideas about what her Health and Wellness course entailed, and what the concept "health and wellness" meant, supporting Kerianne to further articulate information about her course:

KV: Ok, so what is this picture of specifically?

Kerianne: My book.

KV: Oh, it's your textbook.

Kerianne: Yep.

KV: And so, what are people doing in this photo?

Johnny: Like…planting.

Booker: They're gardening.

KV: They're gardening, and Johnny you said "planting"… planting what?

Johnny: Planting plants.

KV: Right. Yeah. And so, do you learn about gardening in this class?

Kerianne: Not yet.

KV: So why do you think your textbook has this picture on the cover then?

Kerianne: I have no idea.

KV: So, if the class is about health and wellness, do you talk about planting plants, or gardening, like Johnny and Booker said?

Kerianne: Yeah. How I should eat more vegetables and fruit. Like now they have to... and

they have to like… they have to like document for... how like... umm… (pauses)… they want us to umm… (pauses), want us to umm... document like (pauses) how much exercise you get.

Without the natural supports of the group in generating possible explanations for why the cover of her Health and Wellness textbook had a picture of people gardening, it's possible that Kerianne may have continued to struggle, or at least may have been unable to generate this level of detail, in describing her academic experiences in the AMP program. In the excerpt above, the group supported Kerianne to move beyond only stating that she's taking a health and wellness class, to describing what she does in that class (e.g. documenting her diet and exercise habits).

Depending on how they manifested, support relationships had the potential to facilitate or hinder students' participation in documenting and representing their college experiences. These methodological data suggest the nuanced and complex role of support staff in conducting research with college students with IDD labels. These data also evidence the methodological possibilities of focus groups in conducting research with participants with intellectual and developmental disability labels. The students acted as natural supports for each other's participation in the research activities, serving as technology trouble-shooters and conversation scaffolders, co-generating data that may have remained hidden in one-on-one interviews (Cambridge & McCarthy, 2000; Carey, 1994; Fraser & Fraser, 2001; Llewellyn, 2009).

The Role of the Researcher

As noted in Chapter 3, I designed this study utilizing a participatory action research (PAR) framework to facilitate students with intellectual and developmental disability labels (IDD) in documenting and representing their college experiences. Informed by the democratic aims of Disability Studies, my goal as a researcher was to try to break down or at least reimagine

conventional researcher/researched relationships and relocate power to the participants (Petersen, 2011). Because of the aforementioned challenges of qualitative research with participants with IDD labels (Arscott, Dagnan, & Stenfert Kroese, 1999; Beail & Williams, 2014; Booth & Booth, 1996; Clarke, et. al, 2005; Harris, 2003; Jones & Stenfert Kroese, 2007; McVilly et. al, 2006; Nind, 2008; Redd, 2004; Scott, 2006), I also designed this study to explicitly inquire about methods, including my methodological memos as data (Conder et. al, 2011; Noffke & Somekh, 2005). I wrote memos about my role in the research process—processing what happened during focus group meetings, and mulling over methodological decisions in hopes of moving closer to my aims of participatory research. Therefore, this section will present the methodological findings from said memos through a discussion of the following themes: 1) Researcher as teacher or authority figure, 2) Flexible data collection and, 3) Participatory research realities.

Teacher or Authority Figure

From the first focus group meeting to the last, the students who participated in this study interacted with me as a teacher, or as the person "in charge," to whom they reported their activities and other goings on (Owen, 2001). I made efforts to interact with the students outside the focus groups, chatting before and after our meetings and attending various social events throughout the data collection period including: a local hockey game, a team-building day at the university's ropes course, and the AMP program's end of the year celebration. Though the relationships we cultivated throughout the data collection period were positive and the focus group meetings were generally informal, the conventions of teacher/student proved too strong to totally dismantle due in part to, as I discuss in greater detail, deeply-engrained cultural expectations of "smartness" that the students consistently performed. Below I include excerpts from my methodological memos (Conder et. al, 2011; Noffke & Somekh, 2005; Owen, 2011) to

illustrate the theme of researcher as teacher/authority figure and characterize how this role manifested despite my pushing against it.

After the first focus group meeting of the semester, I wrote a memo about how it went, clearly aware of my attempts to reject the teacher/authority figure role and connect with the students on a different plane:

I felt nervous and wanted to act 'cool' and 'hip' like college kids, speaking informally. Wow, I'm old. Feeling our 10-15 year age gap. I introduced myself and asked their names. The room quieted like 'shh, the teacher is talking.' I didn't use the terms 'PhD' or 'dissertation,' but explained without jargon that I was also a student and was here to learn about the AMP program so I could help other colleges develop similar programs. Jim and Shannon had their phones out. I remarked that I liked Jim's phone case that had a cut out of the Spiderman logo. He said: 'I made it. I was surprised and said 'Oh, you did?' He said 'Yes, with my 3-D printer.' I looked at it and remarked at how interesting it was and shared 'I really don't understand technology.' (Am I doing what I often do, and working hard to put others in the position of experts? I am cognizant of this often in spaces where I am the only person without a disability. Sometimes I feel that I overcompensate but here I was authentic: I truly don't know how 3-D printers work nor did I have any idea that it could make a phone case.)

Before this first meeting I came prepared with what I thought would be a good ice-breaker exercise to gauge the students' communication styles and preferences, and establish their level of comfort with writing activities. The activity I presented asked the students to share their thoughts about the following:

L. What do you **L**OVE to **L**EARN about? Why?

O. What **O**UTSTANDING talents, abilities or skills do you have?

V. Who is one **V**ERY important person in your life? (It could be a boyfriend, girlfriend or an important friend or family member.)

E. What is one **E**XCELLENT thing about attending Central University?

In my post-meeting memo, I noted:

I already regret having the activity written because it changes the energy, and the idea of being asked to 'write' something has quieted the room and makes it feel like a test or like I'm looking for a 'right answer.' Johnny is having trouble with writing and asks me how to spell various words, and Lawrence is having trouble with knowing what the question is asking, so he is being supported by Irene, an agency staff person who works with him. I asked Irene to participate and offer her ideas as well, and I also did, in hopes of creating a sort of more level playing field (e.g. it's not just me asking the students questions that I'm not also answering, or that the other non-students are not answering.)

From the outset, I was conscious of being the teacher and the focus group meeting being a class, and this theme continued throughout the data collection period. I often noted, regretfully, how the students and the support staff characterized the picture-taking activities as "homework" or "assignments," as seen in this instance when Holly, Victoria's support person, asked me: "Vicky has three pictures that she wants to share for the homework assignment, is that ok?" In the next section I discuss my commitment to a flexible data collection process and detail the methodological changes I made to respond to or curb these teacher/student/homework tendencies.

Perhaps the most striking finding about this theme of researcher as a teacher/authority figure was evidenced by the "direction" of the conversation—that is, during our focus group

meetings, the students mostly spoke to me, asked me questions about other students' photos, or directed their comments about their college experiences (or about seemingly random happenings) towards me (Owen, 2001). In the excerpt below, I shared my puzzlement about this convention:

> They [what the students decide to share about their college experiences] are all these sort-of singular statements that are directed at me. It is the students just sort-of telling me random things about their lives that may have little to do with the conversation at hand, and have little to do with each other. They often are just sort of tidbits about their lives that it feels like they're 'reporting' to me or to the 'teacher.' What does this mean?

Since it's difficult to evidence this finding using transcript excerpts, I selected a sample transcript from one focus group session and mapped the direction and flow of the conversation. Within the hour-long focus group session, there were 18 distinct "topics" of conversation, ranging from figuring out who was planning to attend the AMP and Student-2-Student trip to the local hockey game, sharing news about an upcoming conference in which Jim and Johnny planned to participate, describing the digital photo collages they had made, and a few seemingly non-sequitur interjections. I counted a total of 81 communicative "bids," that included when I addressed the group, when I directed a comment or question towards an individual student, when a student's comment or question was directed towards only me, and when the students talked to or engaged with each other. Forty of the interactions within this focus group session were individual students speaking directly to me (whether or not I initiated said interaction), thus comprising half of the total communicative interactions during that hour. Only eight interactions occurred between the students themselves. This transcript is representative of most focus group sessions, despite my methodological attempts to disrupt or reorganize how the conversations

happened. Below, Figure 2 illustrates the outcome of this mapping process. The figure includes icons representing me, The Researcher, with arrows of varying widths emanating towards icons representing either one student or a group of students. There is also an arrow running between the student icons to represent the few times they engaged directly with each other. The visual illustrates how the conversations and interactions were heavily weighted on me, The Researcher.

Figure 2

Mapping the Conversation Direction
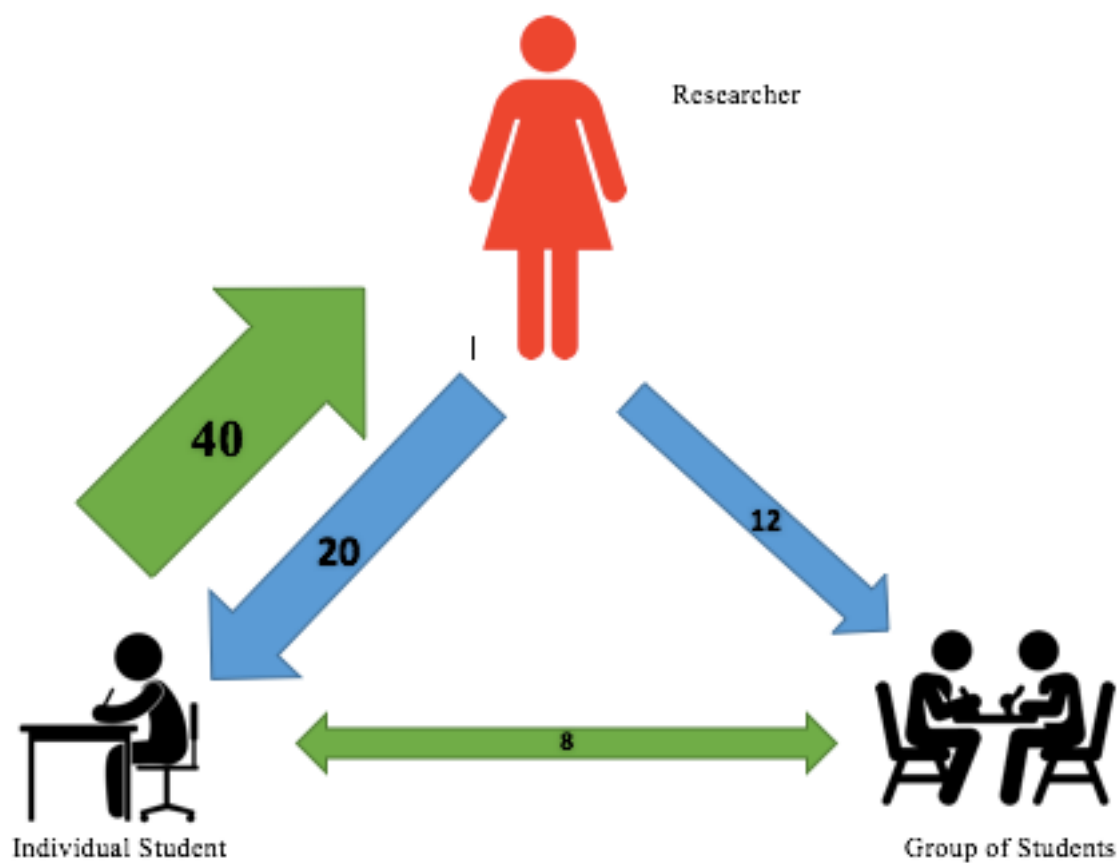
As with many of the findings presented throughout this study, this represents an additional example of how the lens through which the data are viewed has the potential to alter the story that is told about the participants and their lives as college students. What I failed to adequately consider in the moment was how students with intellectual and developmental disability labels—like all students in the American public school system—are acculturated to perform in accordance with certain norms of schooling. Being a "good student" and conceptions of "smartness" are powerful, loaded tropes that, while they largely go unacknowledged, are reproduced in college classrooms across the country, across populations of students, particularly those who occupy marginalized identities. Leonardo and Broderick (2011) concede that it's then not surprising how individuals who have been labeled with intellectual disability seek to "assert their intellectual competence" to begin to chip away at the "ideological state apparatus" of smartness (p. 2221). In Chapter 6 I will extend this analysis of how the students in my study took purposeful steps to adhere to these dominant cultural conceptions of "smartness," especially considering how this is a label that many of them had likely been working to earn and claim throughout their experiences in K-12 schooling.

Flexible Data Collection

In my memos, I pondered ways to restructure the student/teacher tendencies noted above. After one focus group session, I wrote about reframing the picture-taking activities entirely and, rather than having the students go out and take a specific picture about a specific topic, instead ask them to share a picture from their photo libraries or social media accounts:

So, as the sessions proceed and I am rethinking my sort of 'photo quest' method

approach. It doesn't really fit within the students' lives to say: 'Go out and take a photo'

or for them to decide on a particular topic, because they all take and post photos all the

time. The specific 'ask' of the project is potentially limiting what we find, whereas asking the students to pick something to share with the group from the photos they take already, may be a more authentic way for them make choices about what to represent about their college experiences. So anyway, during this session I just asked students to pick a photo of their 'friends' or 'a friend' to share, and use that as a discussion prompt to then springboard into a discussion about friendships in college.

In attempts to redirect the flow of the conversation from always moving from Student to Researcher, I suggested the students use their own devices to show the group, rather than trying to corral the pictures into one place:

> KV: Rather than bother with sending them to me, since that takes up a lot of time, why don't each of you find a picture of your best friends, or really close friends, on whatever device you have (and, if you don't have something here, you can use my computer to log into your Facebook or Instagram), or we can just pass around the phone or iPad or tablet… is that ok?

Additionally, in accordance with best practices for conducting focus group research, I attempted to locate and encourage opportunities for students to interact with each other, rather than report to me (Kitzinger, 1994; Krueger, 1994; Morgan, 1988; Owen, 2001).

In prepping for one focus group meeting, I composed a memo about how I "didn't have much of a plan other than trying to create opportunities for the group to work within themselves and not just answer my questions." In one session, I enlisted Jim and Shannon's help to teach the group how to make a digital photo collage, hoping that placing them in the expert roles would shift the balance of power away from me. There were many instances throughout the transcripts where I redirected students' comments or questions away from me and towards other students.

For example, Shannon shared a picture of her notes from the course in which she was enrolled. Booker asked me what an acronym meant and I attempted to facilitate their interaction, rather than provide the answer myself:

> KV: This is yours… oh ok, so what's this one?
>
> Booker: CFS…? (Looks at me as reads the acronym from the picture that Shannon shared in an inquisitive tone.)
>
> Shannon: These are notes.
>
> KV: Oh, your notes. Oh, ok. Well, (to Booker) why don't you ask her? So, Booker had a question.
>
> Booker: What is a "CFS"?
>
> Shannon: Child and Family Studies.
>
> Booker: Oh.

As Owen (2001) proposes, focus group research with what would be considered "vulnerable populations" is often characterized by participants interacting solely with the researcher or focus group facilitator, rather than with each other. While Owen (2001) suggests this may be because vulnerable individuals have difficulty with verbal communication or social skills, she also notes the possibility that participants harbor beliefs that they have nothing to contribute. Owen's (2001) findings connect specifically to women with mental health challenges, but, as Institutional Review Boards categorize individuals with intellectual disability labels similarly, her findings resonated with my data. Though I made concerted attempts to encourage student participation between each other, I often defaulted to Owen's (2001) approach of asking each student in turn to share their photos or thoughts about the topic at hand. In Chapter 7 I discuss my relative level of success in achieving my participatory research aims and how the

study evolved from its initial PAR design.

This chapter discussed methodological findings about doing qualitative research in focus groups with individuals with intellectual and developmental disability labels. The data discussed herein highlight the multi-faceted and nuanced role of support for research participants with IDD labels, describing how support staff can sometimes facilitate or hinder participation. Additionally, data showed how the students who participated in this study supported each other to represent and describe their college experiences. This chapter also discussed findings about my role as a researcher and how I tried to disrupt or reimagine my relationship with the students. The next chapter, Chapter 6, will discuss the implications of the thematic and methodological findings in conversation with extant research, while Chapter 7 will propose new questions for research investigating the experiences of students with IDD labels in inclusive postsecondary education.

Chapter 6

Discussion

In this chapter I discuss key findings presented in Chapter 4 and Chapter 5. Specifically, I look at what new stories the data tell when considered through the lens of a Disability Studies framework. This chapter provides an opportunity to take a deeper dive into the analysis while also discussing the relative "silences" in the data—that is, in addition to what the students who participated in this study documented and represented about their college experiences, what did they not discuss? What was left unsaid? Disability Studies is a theoretical lens that interrogates and even reimagines assumptions about the body, about representation, and about systems of power that maintain the status quo (Garland-Thomson, 2011). Ruling paradigms of compulsory able-bodiedness and compulsory able-mindedness (Kafer, 2013; McRuer, 2002) interact to create a narrow and specific definition of what it means to be a college student that these findings helped to deconstruct or reimagine. I decided to analyze these data through a Disability Studies lens, in light of the pervasive assumptions about persons with IDD that characterize them as antithetical to academic life. That is, the very nature of intellectual disability conflicts with the meaning and purpose of higher education—a space meant to be reserved for the intellectual "elite" who perform and communicate in normative ways. As Disability Studies is a framework that seeks to understand disability not as bodily impairment, but as a social construction, putting my findings in conversation with Disability Studies ideals revealed new interpretations of the experiences of my participants (Ferguson & Nusbaum, 2012; Fleischer & Zames, 2011; Linton, 1998; Oliver, 1990.) As discussed in Chapter 4, the students represented their college experiences as overwhelmingly positive. For them, college meant developing new friendships, participating in group social activities, exhibiting school spirit, and being regarded as different

people than they were in high school. However, looking at those experiences through a Disability Studies lens tells different stories that uncover tensions about the students' college experiences. This discussion is organized into the following sections: 1) The double-edged sword of program involvement; 2) Different-looking friendships; 3) Paying attention to the silences; 4) Constructing communicative competence; 5) Support staff presence and meaning making; and, 6) Uncomfortable conversations about inclusive postsecondary education.

The Double-Edged Sword of Program Involvement

Much of the literature reviewed for this study noted how there is not yet a consensus on what comprises an "inclusive" postsecondary education experience for students with IDD labels. Thus, one of the research questions around which I organized this study asked: What does inquiring into the experiences of college students with IDD labels teach us about inclusive postsecondary education? Though my goal was not to assess the level of inclusiveness of the students' experiences, my positionality as a strong proponent of inclusive education kept leading me back to that question. I found it almost impossible to avoid scribbling "Is this inclusive?" in the margins of my methodological journal entries or while I coded my transcripts, exposing more about my own assessments of the students' experiences than their own. Thus, the first thematic finding discussed in Chapter 4 helps to answer that question.

In Chapter 4, I presented data about the college experiences of my participants that were largely defined by the many social events and activities in which they participated. The students shared and discussed photographs taken throughout the data collection period documenting apple picking trips, ice skating outings, movie nights and countless university sporting events. Most events the students documented were activities organized or facilitated by the Alma Mater Program itself or by the staff and student leaders of the Student-2-Student program. The students

in this study often touched on how much they enjoyed these activities, and cited the AMP

program's involvement or the Student-2-Student peer leaders' logistical support as key to

making them successful and facilitating their access and participation in the broader campus

community.

In his investigation of the social inclusion of students with IDD labels in an inclusive

college program, Prohn (2014) reported similar findings, describing what he, and the typically-

enrolled college students interviewed for his study, understood as the often-heavy-handed role of

the program staff in the lives of its students. In observing how much control the PSE program

exerted in scheduling the social lives of the students with IDD, Prohn's (2014) typically-enrolled

participants described this as "watered down inclusion" (p. 155). While the students with IDD in

Prohn's (2014) study also reported how much they enjoyed participating in social activities and

events, his analysis suggested that the PSE program's "social stage setting" had the potential to

"create social dependencies" in which, according to the traditionally-enrolled peer "Supports,"

the students with IDD labels might then "inaccurately assess belonging" (p. 170). Additionally,

he proposed that the highly-structured and supported social networks of students with IDD

eliminated any social "risk"—that is, the paid mentors or volunteer peer supports served as

"built-in social partners," decreasing or even eliminating opportunities for students with IDD

labels to navigate "socially ambiguous environments" (Prohn, 2014, p. 174).

What is clear from my data is how hard the AMP program worked to create inclusive

experiences for the students enrolled in their program. The very existence of the Student-2-

Student program suggested that AMP staff anticipated potential barriers to inclusion and sought

to put structures in place to mitigate them. However, there exists a tension between the level or

amount of program-involvement in the lives of the AMP students and if the presence of this

involvement eclipses its inclusive aims (Clement & Bigby, 2009; Cummins, 2005; Prohn, 2014). For example, some self-determination literature suggests the need for individuals with IDD labels to live, work and learn in contexts that permit them control of their own social experiences, thus begging the question: how do inclusive PSE programs achieve balance between supporting students to access social experiences and supporting students to control their own social experiences? (Abbot & McConkey, 2006; Wehmeyer & Garner, 2003).

It's on this shifting stage that both a Disability Studies and feminist reading of these data is most helpful and allows me, and this study, to live (though a bit restlessly) with some ambiguity. While it behooves PSE programs to institute more flexible structures that allow students to experience "the dignity of risk" (Perske, 1972) in hopes of sustaining high qualities of living not only in college but beyond, Prohn's (2014) analysis does not leave a lot of room for ambiguity in terms of how he positions his participants' membership and belonging within the campus community. Perhaps most strikingly, it was the non-disabled peer Supports in Prohn's (2014) study who assessed the social inclusion of their disabled peer partners as less authentic because it was, in their view, so heavily facilitated and structured. As illustrated in the data included in Chapter 4, the students in my study communicated a more nuanced understanding of the role of the AMP program in their lives. Johnny, for example, acknowledged that the program-organized emails alerting him and others of planned social activities were a key component of facilitating his access and participation, so much so that expressed a strong desire to still stay on the email list after graduating. After the AMP program took a more active role in facilitating the students' access to campus and community events, Jim reported how much more he enjoyed it because, "now we do anything and everything together." I concur with Cowley and Bacon (2013) who propose that a Disability Studies-informed understanding of self-

determination is a possible way forward. They posit that while the well-intentioned aim of self-determination scholarship is to encourage the development and expression of agency for individuals with disabilities, much of the rhetoric rests in understandings of intellectual disability that continue to canonize ableist notions of independence, autonomy and self-sufficiency or what Charlton (2006) calls "the ethos of individualism" (p. 218). This study answers Cowley and Bacon's (2013) call for research that "targets the voices of students with intellectual disabilities" (p. 481) while Disability Studies and feminist notions of interdependence and mutual support (Abery & Stancliffe, 1996; Davis, 2002) help me to widen the scope of my analysis beyond black and white questions of "inclusive" or "not," and create space for future inquiry to fill.

Different-Looking Friendships

As presented in Chapter 4, the students in this study described the integral importance of friendships in shaping their positive college experiences. Students shared and discussed photographs representing the strong connections they forged with traditionally-enrolled students who volunteered as peer partners for the Student-2-Student program and with other AMP students. They rarely discussed friendships with individuals who were not part of these two groups. Much of the previous literature about the social networks of individuals with IDD labels raises issues of reciprocity or authenticity. That is, because of the highly segregated educational placements of students with IDD labels in K-12 settings (Kurth, Morningstar & Kozleski, 2014), there exist few opportunities for individuals with and without disabilities to develop meaningful, reciprocal relationships. Therefore, how do we understand the dynamics of the friendships represented in this study in conversation with previous scholarship, and, what do these experiences tell us about inclusive postsecondary education?

Rossetti (2011, 2012, 2014, 2016) has conducted considerable research about friendships

between individuals with and without disabilities, namely intellectual and developmental disabilities. In a 2011 study focusing on relationships between high school students with and without disabilities, Rossetti (2011) defines friendship in a way that emphasizes authenticity, reciprocity and agency:

> Reciprocal and meaningful relationships that are chosen individually, occur outside of friendship programs, and are based on shared interest . . . These relationships are not "helping the handicapped" and are not based on benevolence or one-way helping but share in the value of human reciprocity (Rossetti, 2011, p. 23).

Across this body of literature, Rossetti and Keenan (2017) reported several themes salient to my findings. First, friendships between individuals with and without more significant disabilities are possible, they just might "look different" than friendships between typically-developing peers. Drawing on scholarship from Anderson et. al, (2011) and Evans and Meyer (2001), Rossetti and Keenan (2017) explained these differently-manifesting relationships were due to factors such as, for example, communication norms. Many friend pairs possessed one person who might not communicate using physical speech, therefore the use of augmentative and alternative communication (AAC), sign language, or other non-verbal communicative behaviors painted a picture of a relationship that, while reciprocal and mutually-beneficial, looked atypical. Most salient for my findings, friendships between individuals with and without disabilities also looked different due to the relatively limited availability of what Rossetti and Keenan (2017) termed "shared time." That is, individuals with and without disabilities tended to congregate around planned activities or events, often due to access needs connecting to disability (sensory, mobility or other physical needs) or availability of reliable transportation (Anderson et. al, 2011; Rossetti, 2011). My findings confirmed these trends since the students who participated in the

AMP program did not live on campus and, save for Chris who had a license and a car, relied on family, support staff or peer partners for transportation. Thus, shared time with their friends was often limited to planned social activities where logistics were accounted for, presenting few opportunities for spontaneity. The friendships of some of the students in my study also "looked different" because of what Siperstein et. al. (1997) identified as the sometimes "hierarchical nature" of relationships between individuals with and without disabilities. For example, though ultimately describing them as his "friends," Jim labeled Student-2-Student peer leaders Reba and Kevin as the "den mother and den father" of the AMP program, characterizing their roles as somewhat parental. This wasn't the only instance where Reba and Kevin were depicted in hierarchical ways. Booker shared information about Reba coordinating a group trip to the movies, while Shannon described an instance where Reba had to run interference with university event staff to ensure that the AMP students were all able to sit together at a basketball game. Incidentially, the Student-2-Student program employed a third student as part of the team of peer leaders who was a student enrolled in the AMP program. However, my participants did not cast this third peer leader in a parental role, nor did he figure strongly in the data. Though there were not instances where my participants characterized the AMP student peer leader as inherently different than Reba or Kevin, his relative absence from the data suggests that the AMP students in my study may have viewed him in a different light.

Next, Rossetti et. al. (2011) reported findings from previous literature about friendships between individuals with and without disabilities that discussed the role of support or help in these relationships. Many studies reported that relationships between individuals with and without disabilities were often forged under the guise of help or support, from the non-disabled person to the disabled one (Anderson et. al., 2011; Evans & Meyer, 2001; Rossetti, 2011; Van

der Klift & Kunc, 1994). I hesitate to draw similar conclusions from my data, since I did not

elicit the perspectives of the typically-enrolled students who participated in the Student-2-

Student program, and so it remains unclear if support and help went "both ways." However, the

data from Shannon, specifically, demonstrate her recognition of this very tension. As Shannon

noted, though she considered her peer partner Abby "more just like my friend," Abby ended up

taking a paid position as a peer mentor to support Shannon in one of her courses. Shannon

understood the ambiguity in characterizing Abby as "just a friend" when part of their relationship

included time spent together for which Abby was paid. Staub et. al. (1994) found that individuals

without disabilities who were identified as "friends" of individuals with disabilities were actually

slated for tutorial or other support roles by parents, teachers or other support staff, thereby

creating dynamics that included one-way help or support that might not otherwise have arisen.

Shannon's experience confirms this trend, as she noted how Abby "had to be my mentor,

because there were no other mentors," implying that someone from the AMP program may have

approached Abby to take on this new role, knowing that they were already friends. Bacon,

Orsati, Floyd and Khater (2017) also highlighted tensions that arose in defining friendships

between individuals without disabilities who serve in support roles for individuals with

disabilities. In their co-authored article, Floyd, an individual with autism who types to

communicate, details the ambiguity he feels when forming friendships with people who also

serve in paid support roles: "A friend means someone who…each week…has a good way of

interacting, so that I am fully sure that they forget about the money or school credit for being

around me" (Bacon, Orsati, Floyd & Khater, 2017, p. 13). Though she also considered Floyd a

friend, Bacon shared her own discomfort in receiving compensation for time spent with him: "I

tried to convince myself that the paid time I spent with him was in fact quality time…I struggled

with the idea that I would not get similarly compensated to spend time with other friends"

(Bacon, Orsati, Floyd & Khater, 2017, p. 13). However, Rossetti and Keenan (2017) found that,

across the friendship literature, adult intervention (whether teachers, parents or program support

staff) provided the necessary impetus for authentic, reciprocal friendships to eventually develop

between students with and without intellectual and developmental disabilities. Whether taking

the form of modeling positive interactions or supporting communication or mobility, research

shows that adults served critical roles in initiating or facilitating relationships between groups of

students that, due to the schooling and societal structures of which they are all a part, might

otherwise remain separate (Cuckle & Wilson, 2002; Evans & Meyer, 2001; Matheson et. al.,

2007; Rossetti, 2011; Turnbull, et. al., 2000). While the discussion in the previous section

assumes a somewhat dubious perspective about the role of the AMP program in facilitating

social experiences for its students, the literature about friendships characterizes this role as not

only positive, but necessary.

Social networks of individuals with IDD labels are often quite small, comprised primarily

of family members or paid support staff (Biklen, 2005; Clement & Bigby, 2009; Cummins &

Lau, 2003; French & Swain, 2001; Marquis & Jackson, 2000). However, the students who

participated in this study and other studies of inclusive postsecondary programs reported

expanded networks comprised of typically-enrolled students who served in volunteer peer

support roles (O'Brien, 2009; Paeiwonsky, 2011; Prohn, 2014). Additionally, my participants

often shared and described photos depicting their close relationships with other AMP students.

The AMP students evidenced a strong program cohesiveness that manifested in them

participating in various university spaces as a distinct cohort. Admittedly, this finding could be

read as reproducing "special" or segregated spaces for individuals with intellectual and

developmental disabilities that the aims of inclusive postsecondary education programs purport

to actively work against. It could also serve to confirm attitudes and practices embedded in

traditional special education structures (Brantlinger, 2005; Ferri, 2009) that students with

disabilities somehow require their own, separate contexts, as opposed to, as Woodfield (2016)

suggests, simply mean that these particular students valued each other's company and elected to

spend time together. This is one of the findings I most often bring up when speaking with

colleagues about my dissertation research. In recent years, I have come to appreciate "disability-

only" spaces and places as chosen, positive, and culturally-affirming in, for example, the Deaf

community or the Autistic community. In interrogating where the "least restrictive environment"

is for Deaf students, Singer and Vroman (2018) note that as Deaf residential schools continue to

close and students are educated in their neighborhood public schools, there exist fewer

opportunities for Deaf cultural identity transmission. Deaf and Autistic cultural groups challenge

my deeply-entrenched commitments to inclusive placements as the "best" settings for individuals

with disabilities to achieve the most positive academic *and* social outcomes (Singer & Vroman,

2018). Sinclair (2010) echoes this sentiment in writing about a preference for culturally Autistic

spaces where "Autistic people determine what our needs are, and autistic people make the

decisions about how to go about getting our needs met" (Sinclair, 2010, Autistic Space vs. Places

for Autistics section, para. 5). Rightly anticipating how this idea might be taken up by "NTs"

(non-Autistic or "neurotypical" people), Sinclair (2010) raises key questions to ask in defining

"Autistic Space" vs. "places for Autistics": Who creates these places and spaces? Who controls

how, where, and for what purpose they are formed? Who makes the rules? Sinclair (2010)

concedes that well-trained, well-meaning "NTs" can facilitate positive environments in which

Autistic people can learn, live and work, but they are ultimately *not* culturally Autistic Spaces if

NTs are the ones in charge.

For now, there's something about "Intellectual Disability Culture" or "Intellectual Disability Spaces" that still feels uncomfortable. I locate some of that discomfort in what I see as risk: will my findings be wielded in ways that will serve to marginalize and potentially re-segregate a population of students who are just beginning to define their membership in postsecondary education? Is there a way for people with intellectual disability labels to actively seek or choose each other's company and have that be read as intentional, positive, culturally-sustaining decisions, as opposed to: "See, I told you *they* needed to be around *others like them*." As with all my findings, the best and most nuanced answers to these questions lie in the fruitful gray area between what I am coming to understand as a false dichotomy. Perhaps the students in my study can and are choosing both—to be members of an affinity group from which they draw pride, fulfillment, friendship and other benefits of shared experience, while also being woven into the fabric of the larger university community that itself boasts other cultural affinity groups? Scholarship that documents the lived experiences of other marginalized groups with multiple identities illustrates similar sentiments. For example, individuals who identify as biracial or multi-racial, queer, or as undocumented immigrants, are presented with the same false dichotomies of needing to choose one identity or affinity group to live in at all times, instead reflecting emphases on intersectional identities between which they "cross borders" (Abes & Kasch, 2007; Giroux, 1992; Reyes, 2017; Root, 1996; Valdez & Golas-Boa, 2018). Valdez and Golas-Boa (2018) found that among college students who identified as undocumented immigrants, they derived an overall sense of campus belonging from multiple, intersecting facets of their identities, as opposed to their status as undocumented operating as a "master status" (Hughes, 1945; Valdez & Golas-Boa, 2018). Similarly, literature about culturally Deaf

individuals who elect to get cochlear implants, notes the "both/and" nature of what it means to claim a marginalized cultural identity while also moving in and through the dominant, hearing world (Bathard, 2014; Mauldin, 2016), acknowledging the shifting, contextual nature of individuals with multiple, intersecting identities. Depending on the demands of the environment, individuals may elect (sometimes subconsciously) to lead with one facet of themselves, or, they may be narrowly read by others as only one thing. What gives me pause is work from scholars such as Couser (2005) and Shakespeare (1996), who argue that disability is so "fundamental" that it often does act as a "master status," eclipsing other identities and serving as their "primary defining characteristic" (Couser, 2005; p. 120), if not by themselves, then by others. For college students with intellectual disability labels, and for the students in my study, the data showed that their academic and social worlds are still so structured by non-disabled "others," that I continue to be troubled by if, or to what extent, their multiple identities will be not only acknowledged but celebrated?

What About "Disability" Itself? Paying Attention to the Silences

While attending a regional summit with other inclusive postsecondary education professionals, I broached the tension I described above and, in reply, a colleague offered: "Well, I get your apprehension, but for me, as a young gay man, I immediately found the other gay students when I went to college. First you have to belong *somewhere* before you have the confidence to branch out into other communities." While the comparison between the disability experience and the LGBTQ experience does not perfectly align, my colleague's comment incited important questions about the contours and conflicts of intellectual disability affinity and identity. It's important to note that I did not explicitly ask my participants about identity. I did not ask them how they defined themselves in relation to disability, or if they considered

themselves disabled. Rather, our focus group conversations followed the students' leads, rarely, if ever, explicitly mentioning the term "disability," or discussing it in great detail. In this section, I elaborate on this finding, or rather, this absence, and propose various interpretations for why this might be the case.

A Disability Studies reading of the college experiences of students with IDD labels has uncovered new understandings (and invariably new questions) about how these students aligned with or resisted the forces of compulsory able-bodiedness and compulsory able-mindedness as they entered postsecondary education spaces (Carlson, 2001; McCruer, 2002). As suggested by Ashby (2011), qualitative research that investigates the experiences of individuals with more significant disabilities must also pay attention to the proverbial silences, or gaps in the data—i.e. in addition to what my participants showed and said about what it meant to be college students, what remained unsaid? Upon listening back to the initial focus group meeting recordings, I picked up on a previously-unheard side conversation between Booker and Irene (Lawrence's support staff member who attended the first few sessions). I do not know the larger context for Booker's question, but heard him ask Irene: "What's a disability?" Irene paused and clarified Booker's question: "Did you ask me, 'what is a disability?'" He affirmed her clarification and Irene replied, sounding unsure of how to answer: "Umm… a disability is when… when someone has trouble doing something." It's unclear if Booker was satisfied with the explanation as the group conversation quickly moved in a new direction, but upon writing this chapter, Booker's question gave me pause. I revisited my transcripts and, save for a few references to the word "disability" or allusions to "being in special ed," the students rarely, if ever, talked about themselves as disabled or as people with disabilities. In one instance, Billy and Victoria talked about attending a World Down Syndrome Day event, while another time Jim brought up an

episode of "The Big Bang Theory" that addressed disability. Johnny briefly touched on his challenges with reading and writing and talked about the marginalization he felt in high school because of his membership in "special ed," but by-and-large, disability was not something that the students discussed. Below I propose four different ways to interpret these silences, depending on how intellectual disability is framed or understood: 1) The students don't know they are disabled; 2) The students have been denied access to language and discourse about disability; 3) The supportive environment of the AMP program served to "erase" the disabling effects of the students' diagnoses; 4) The students' quests for belonging manifested in an overall climate of sameness.

Interpretation 1: The students don't know they are disabled. Dominant, medically-informed notions of intellectual disability would understand these data, or lack thereof, as confirmation of deficit-based diagnostic characteristics of IDD. Proponents of definitions of IDD that highlight cognitive deficits or low IQ scores would likely find it unsurprising that the students didn't talk about themselves as people with disabilities because they don't know or don't understand what that means, and how it applies to their lives. Though I do not agree with this interpretation, a rationale for this finding might read: The students' very membership within this disability category is sufficient evidence to explain why the subject rarely arose.

Interpretation 2: The students have been denied access to language and discourse about disability. Though they may sense some differences between themselves and their peers because of the spaces in which they have moved (or been moved) throughout their schooling careers (e.g. segregated special education classrooms, segregated social activities, or segregated recreation opportunities), the students did not often talk about disability because they have been denied access to dialogue and discourse about their bodies, their support needs or their identities.

Previous studies have found that, particularly for students with IDD labels, presumptions of incompetence about their ability to understand or participate in conversations about their educational and social lives dictate decisions that routinely exclude them from said conversations (Cano, Vaccaro & Newman, 2015; Stodden, et. al, 2003). In fact, leaders in self-determination research report that individuals with IDD labels do not participate in decisions about their postsecondary lives as much as individuals with other disabilities (Carter, et. al., 2013; Shogren & Plotner, 2012; Shogren, et. al, 2008). Learning key skills associated with self-determination such as decision-making, goal-setting and self-knowledge requires not only capacity, but also opportunity to apply these skills in relevant contexts (Cowley & Bacon, 2013; Shogren, et. al., 2008; Wehmeyer, 2005). Subsequently, recommendations for this population of students highlight the need to create more purposeful opportunities for consultation of all students with disabilities in their IEP meetings, medical appointments, and transition plans for life after high school (Cowley & Bacon, 2013; Carter et. al, 2013; Shogren, et. al, 2008; Wehmeyer & Abery, 2013).

Interpretation 3: The supportive environment of the AMP program served to "erase" the disabling effects of the students' diagnoses. The students didn't see themselves as disabled because they existed within a supportive ecology that planned for and supported their access to and participation in all aspects of college life. This possible explanation for the relative "silences" with regards to explicit talk about disability suggests that the social model of disability informed how students were seen, or how they saw themselves. That is, as the social model locates disability in the environment rather than the individual, it's possible that students didn't talk about disability because they didn't experience disabling environments—their access to college was facilitated in ways that eliminated many of the barriers they may have experienced

in their previous educational careers (Linton, 1998; Oliver 1990; Shakespeare & Watson, 1997). Some scholars suggest that the social model and social-ecological model of disability serve to reconceptualize the meaning of "intellectual disability" itself, no longer defining it in absolute terms (Kliewer, Biklen & Petersen, 2015; Schalock, et. al., 2007). Additionally, social-ecological concepts of intellectual disability offer ways to locate intellectual disability the environment, rather than in the individual, and thus, thanks to the individualized supports that bolstered the lives of the AMP students, this label did not fit their experiences, or did not characterize their understandings of their identities (Kliewer, Biklen & Petersen, 2015; Schalock, et. al., 2007).

  Interpretation 4: The students' quests for belonging manifested in an overall climate of sameness. As is often the case in qualitative research, the data led me to believe that the most fitting interpretation is more nuanced than any one of those discussed above. As O'Brien (2009) found in her study of the college experiences of students with IDD labels, participating in postsecondary education affected not only how the students viewed themselves, but how they were viewed by others: "Our mentors are not treating us like we have disability. They are treating us more like ordinary people....they have not got a disability and we have got disabilities and like they don't treat you like a kid. (S1, FG3)" (O'Brien et. al. 2009, p. 290). Though O'Brien (2009) characterized this finding as "student as a different person," what is most striking to me is how the student in the above excerpt articulated "a different person" as "more like ordinary people." Additionally, as noted in Chapter 4, college students interviewed in Think College's short documentary, "Rethinking College," echoed similar sentiments: "You're a college student, you're a human being, you're the same thing here" (Think College, 2013). This resonated with many of my participants' understandings of themselves as college students: while they felt different from how they did in high school, that difference often manifested in feelings

of sameness with others. Perhaps most evident in Shannon's reluctance to draw boundaries

between herself and her typically-enrolled peer partners, Jim and Chris's frustration with not

receiving comparable credentials if they "do all the same work," or Johnny's observation about

no longer feeling the differences between himself and his peers, the students who participated in

this study seemed to understand college as replete with opportunities to disregard their disability

labels and be just like everyone else. In Wilson and Brune's (2013) anthology about disability

and passing—that is, people with disabilities (or other marginalized identities) taking action to

"conceal their impairments to avoid the stigma of disability and pass as 'normal' (Selznick,

2014, para. 1)—Carey's chapter about intellectual disability is particularly incisive here. She

outlines the history of intellectual disability and passing, noting its roots in the Eugenic period

where people labeled "feebleminded" were feared and thus made "visible" by diagnostic and

segregating structures, necessitating that they attempt to pass as normal to remain in their homes

and communities. Carey (in Wilson & Brune, 2013) then describes the tensions of the

contemporary self-advocacy movement, noting the contradictions present in disability pride

narratives that require disabled people to unequivocally identify as such, "stigmatiz[ing] the

decision to pass as conforming to hegemonic ableism" (p. 156). However, drawing from self-

advocate Tia Nelis, Carey proposes that, particularly for individuals with intellectual and

developmental disability labels, claiming that identity is fraught with complexities because of the

risk of bullying, education and employment discrimination, and overall stigma: "I think it is

really hard for people with developmental disabilities to… stand up and say, 'I am retarded and I

am proud,' because of all the [bad] stuff that goes with it" (as cited in Wilson & Brune, 2013, p.

158). Carey suggests that the continued prevalence of "specialized systems" for individuals with

intellectual disability labels including segregated recreation opportunities, sheltered workshops,

and special education, "continue to create sharp distinctions between the abled and disabled,

heightening tensions around passing and removing people's choices about how to identify" (as

cited in Wilson & Brune, 2013, p. 143). Thus, it's possible that in the supportive, inclusive

environment of the AMP program, the widespread absence of disability from the data actually

reveals the students' intentional, strategic acts of resistance where, in the context of our

discussions of their photographs, they exerted agency and choice over how to define and

represent themselves. The final chapter will revisit this discussion and propose future research

that investigates intellectual disability identity, particularly within a postsecondary education

context.

Constructing Communicative Competence

In Chapter 5, I presented data to illustrate the finding about what I called "seemingly non-

sequiturs." Throughout my data collection process there were times when most of the students

who participated in this study would contribute to the focus group discussions in unexpected

ways, at inappropriate times, or take the conversation in entirely new directions. These findings

could be read as further evidence that individuals with IDD labels are a "difficult" population to

include in qualitative research studies, because of documented challenges regarding perceived

inarticulateness, tendencies to answer in ways that will please the researchers, or the inability to

think in abstract terms (Beail & Williams, 2014; Booth & Booth, 1996; Clarke, et. al., 2005;

McVilley, et. al, 2008). However, a Disability Studies reading of these findings offers alternative

explanations for what might be going on that will thus allow qualitative researchers to

purposefully construct communicative competence for participants with IDD labels (Biklen &

Kliewer, 2006).

As noted in Chapter 5, Chris and Kerianne were two of the students who most often

participated in group discussions in these seemingly non-sequitur ways. No matter the topic, Chris seemed to always shift the conversation back to sharing information about his job at the zoo, or his future plans to attend the local community college. Meanwhile, Kerianne's non-sequiturs often manifested in her telling me about her previous or future weekend plans to visit family, or updating me about the cold from which just recovered or the upcoming ear surgery she had to undergo. Though the ten students who participated in this study knew each other and seemed to generally boast a positive rapport, Chris and Kerianne rarely appeared in pictures of AMP program group events or outings. Ironically, even though Chris was the only participant who had a car and a driver's license, his work obligations prevented him from attending the social activities that figured so prominently in the lives of the other students. Knowing how his opportunities for socializing were thusly limited, it's easier to read Chris's frequent and consistently-themed non-sequitur comments as intentional, serving to deflect attention away from his relative disconnection with his program cohort. Chris was isolated from the AMP program "in-group" by virtue of what many would consider evidence of his increased levels of independence (his car and his job). Similarly, Kerianne was the only participant who lived independently from her parents—renting the second-floor apartment of her brother's house. However, though she lived in close proximity to her family, the town in which she lived was upwards of thirty minutes away from CU's campus. Though the data collected for this study did not offer additional evidence for why Kerianne did not choose to or was not able to attend the AMP program social events, her absence served to exclude her from conversations about basketball games, movie nights at Reba's house, or trips to local restaurants. It's possible that her non-sequitur comments allowed her to say something about what she valued, even if that something was not connected to the overall themes of the group discussions.

Also in Chapter 5, I discussed an instance when Victoria offered a seemingly non-sequitur comment about participating in a cooking class, interrupting Jim's reflections about his first days and weeks in the AMP program. As it was uncharacteristic of Victoria to be overtly rude or to speak out of turn, I revisited the transcripts to investigate the larger context of her participation throughout the data collection period. In doing so, I noticed that both she and Johnny tended to add information to conversation topics that had previously passed by. That is, while the rest of the group was already discussing a new topic, Victoria or Johnny would interject with comments that related to something that arose five to ten minutes prior. Norms of group conversation privilege individuals who are able to spontaneously share information verbally, or those who boast speedy language processing skills (Ashby, 2011; Ashby & Causton-Theoharis, 2012; Biklen & Kliewer, 2006). Literature that documents class participation trends of students for whom verbal communication is either challenging or absent help to contextualize Victoria and Johnny's unexpected or inaptly-timed comments. For example, individuals who are d/Deaf or hard-of-hearing (Stinson, et. al., 1996), those for whom English is not a first language (Ellwood & Nakane, 2009; Rocca, 2010), or those who utilize augmentative and alternative communication (AAC) systems (Ashby, 2011; Woodfield, 2016), all experience "lag times" in not only receiving communication but also producing it. In delving deeper into these seemingly non-sequitur comments, the data showed how the pace of the focus group conversations did not always create supportive environments in which the voices of Victoria and Johnny could be accessed. Ashby (2011) proposes reconceptualizing how qualitative researchers should think about voice:

> …If we think of voice more broadly as the ability to express oneself and be heard by
> others, that can encompass typed text, non-verbal communication, gestural

communication or silence, which leaves the door open for a more expansive

conceptualization of participation and engagement (Ashby 2011, Broadening the

conceptualization of voice beyond verbal speech section, para. 5).

By "listening in the cracks" (Mazzei, 2009, as cited in Ashby, 2011, para. 5), I was able

to identify and then assign meaning to things which may otherwise have gone unnoticed, thus

moving closer to constructing communicative competence for my participants and allowing them

to render more faithful accounts of their own experiences (Goode, 1994).

Also presented in Chapter 5, I found that the students who participated in my study

interacted with me as a teacher or authority figure. Despite my epistemological and

methodological orientation that prioritized feminist and Disability Studies-informed approaches

to the study's design, this trend persisted throughout the data collection period. While dominant

interpretations of individuals with intellectual disability labels characterize them as overly

compliant or obsequious due to perceived cognitive deficits, Hatt's (2011) idea about

intelligence or, what she terms "smartness," not as an intrinsic, biologically-determined reality

but as a "cultural practice," has noteworthy implications for these data. In investigating how

students as young as five or six years old were positioned as "smart" or not, she found that

students' "smartness" was largely connected to their racial, ethnic or socioeconomic

backgrounds and their abilities to replicate White, middle-class, normative behaviors. Hatt

(2011) drew on Holland et al.'s (1998) concept of "figured worlds," that "represent the rules,

guidelines, or social forces that influence but do not completely dictate the ways people speak,

behave, and conduct their practice within social spaces" (p. 7). In thinking about why the

students interacted with me as a teacher or authority figure, Hatt's (2011) work offers an

understanding of this finding as largely connected to the institution of schooling and its "figured

world" that carries with it immutable norms about how you sit in a classroom, how you participate in a group discussion, how you talk to your teacher, what you say and what you don't. Holland et. al. (1998) remind us that "one's history-in-person is the sediment from past experiences upon which one improvises, using the cultural resources available, in response to the subject positions afforded one in the present" (p. 18). As Hatt's (2011) study focused on the steadily-emerging figured worlds of kindergarteners where smartness was wielded as a tool of control and social positioning, it's not at all surprising that the college students in my study performed in ways that replicated what they had been taught to do to be not only "good" students, but "smart" ones—especially if "smart" in the dominant sense was a category from which they were systematically excluded (Broderick & Leonardo, 2016).

As I continue to wrestle with why my participants and I often interacted in ways that reproduced these performative roles of me as teacher and them as "good" and "smart" students, I acknowledge how easy and free from risk this analysis is for me. My social location positions me as someone whose intelligence, competence or smartness is, in most settings, never questioned. As I noted in Chapter 1, as a White, non-disabled, almost-doctor with a professor partner and professor parents, the privilege and social capital I enjoy permits me to engage in these philosophical acrobatics and, within these pages, call into the question the value of smartness. Even as I agree with Leonardo and Broderick (2011) who rightly express concern with "the costs that marginalized communities bear when appropriating such benign-seeming tropes" (p. 2222), I can't yet envision a reality where my participants would ever not want to gain access to smartness. Thus, I suspect that during my data collection, we all performed our roles accordingly. My educator (and, in this particular moment in my life, maternal) instincts to facilitate, to support, to encourage and to find ways for my participants to showcase their

competence, their smartness, interacted with the students' desires to meet my high expectations

and perform successfully, creating our study's not-so-unique ecosystem of classroom, teacher

and students. A few years ago, during a conversation with a faculty member, the topic of which

is lost to me now, I remember using the phrase: "It was really intellectually challenging, I loved

it!" and then almost immediately being struck by the privilege I enjoy for being allowed to say

something like that without experiencing adverse consequences. For my participants who are

labeled and regarded as intellectually disabled, if they were to echo this sentiment, it would

likely carry not only a different meaning, but perhaps an opposite meaning, thus setting into

motion an inevitable cavalcade of supports and services, because we don't yet know any

different.

Support Staff Presence and Meaning Making

As described in Chapter 5, the presence of paid support staff fundamentally changed the

focus group environment for both the students who were the "clients" of the staff present and

those who were not. What warrants additional discussion here is how the presence of support

staff also changed how the students made meaning of similar photographs and what that meaning

ultimately was. Though this is not a theme for which there were a lot of data to support (namely

because of my methodological decision to ask staff members not to return after the third focus

group meeting), a Disability Studies reading of the entire data set invites and encourages raising

this point. Disability Studies scholarship notes that individuals with intellectual disability labels

are often read as perpetual children or as asexual (Carey, 2009; Desjardins, 2012; Winges-Yanez,

2013), while also highlighting the paternalism that can inform non-disabled peoples' attitudes

and assumptions about intellectual disability (Biklen & Duchan, 1994; Bogdan & Taylor, 1992;

Carey, 2009; Winges-Yanez, 2013). Viewing the following excerpts through this theoretical lens

presents salient, though not unproblematic, implications about the role of support staff in the lives of college students with IDD labels. I acknowledge the challenge of relaying tone of voice in transcribed audio recordings without assigning meaning that the speaker did not intend. Thus, in the conversation excerpts included below, I utilized parenthetical observer comments (OC) and expanded field notes (EF) to produce a faithful rendering of what was said and how it was said in these two separate discussions of Billy's photographs. The observer comments were made at the time of data collection while the expanded field notes were added at the time of transcription. While I followed these data collection and transcribing processes throughout the study, they are particularly useful to make meaning of the instance included below.

Throughout the data collection period, Billy shared photos and stories about his strong community of friends and family from his hometown. He often talked about Kristen, his best friend from home, and she showed up in many of the photos he shared during the focus group sessions. Though data were not collected about Kristen specifically, she appeared to be an individual without a disability and, as Billy relayed, a friend who also served in an informal support role for him. The first time Billy shared a photo of him and Kristen, the support staff people (Holly who worked with Victoria and Amy who worked with Billy), were present. In the excerpt below, Holly had a strong reaction to Billy's photo:

(EF: Next picture comes up – Billy and a blonde girl wearing a baseball hat. The girl is kissing Billy on the cheek and Billy looks at the camera smiling – he is taking the photo, it's a selfie – so it's close up. There is a crowd of others around so it appears it was taken at a basketball game.)

(OC: The groups says: Awwww.)

Holly: Who's *THAT*, Billy??? WOOOOO! (Laughs loudly.) Who is *THAT*, Billy? Look

at you!

(OC: Others are giggling and smiling – mostly the support staff in the room.)

(EF: There is a young man in the shot who looks like he's accidentally in the photo and so his face looks mad – though he was probably just caught at an off moment since he was not actually part of this photo.)

(OC: Whooping, hollering and "Oooooos" continue.)

Holly continues: Look at that guy in the back! Looks like you just *STOLE* his girlfriend!

(OC: Holly laughs again and Amy cocks her head to the side and smirks at Billy.)

Holly: Billy! You can't go around stealing people's girlfriends! (OC: Holly continues laughing.)

KV: Billy, who is that?

Billy: That's my friend Kristen. She goes to high school at Monrovia (EF: Monrovia is the town where Billy is from).

KV: And so, do you know that guy in the back?

Holly (interrupts): You *STOLE* his girlfriend! (OC: Laughs loudly again.)

Billy (OC: Blushes and looks a little sheepish): No no, we're friends. Just friends.

A few weeks later, when there were no support staff members present, Billy shared another selfie taken with Kristen. The other students remarked at how cute the photo was, and suggested that Billy and Kristen become a couple:

(OC: Billy gets his phone ready and shows group. He shares a selfie that shows Kristen kissing Billy on the cheek. They appear to be in a car and Kristen is in the driver's seat.

EF: This seems to be their selfie "pose" since it was similar to the photo he shared in a previous session.)

Johnny: Aw, that's a good picture.

Victoria: That's a cute picture of Kristen and Billy.

KV: So, Billy, remind me of who this is again?

Billy: Kristen Daniels.

KV: So, you guys do this pose a lot, huh? This is a classic Kristen and Billy pose?

Billy: Yeah!

Lawrence: Aww, isn't that sweet.

Booker: Oh, that's a different Kristen. (EF: Not the Kristen who participates in the Student-2-Student program that many of the participants know.)

Billy: Yeah.

Booker (to Billy): Are there more in there? (EF: More pictures in the same series)

Billy: Yeah. (OC: Swipes through a few similar images of them making silly faces in the car.)

Booker: Well, that's love right there! You guys should be a couple.

Billy: Yeah, I do too.

Without the presence of the support staff, the tone of the discussion changed, and the meaning made of Billy's similar photographs also changed. In the first excerpt, Holly's joking, almost mocking, tone seemed to suggest that Kristen couldn't possibly be Billy's girlfriend. In fact, she made a joke about Billy "stealing" the girlfriend of the other not-visibly-disabled person in the picture. Without the presence of Holly or the other support staff, an almost identical photograph was understood quite differently. While the second photograph still elicited a few "awws"—it was objectively a cute photograph—Johnny, Victoria, Lawrence and Booker each expressed how much they liked it. Booker's remark of "That's love right there!" was offered

with sincerity. The students interpreted a series of selfies of these two young adults, smiling, kissing each other on the cheek, and looking happy, as an authentic, budding romance.

Literature about the role of support staff or, in schooling contexts, teaching assistants or paraprofessionals, in the lives of individuals with intellectual and developmental disabilities documents similar trends. Particularly with regards to developing and maintaining social relationships, the presence of support staff has the potential to facilitate or hinder these relationships (Giangreco et al., 1997; Malmgren & Causton-Theoharis, 2006; Rossetti, 2012). Giangreco, et. al. (1997) suggests that paraprofessionals' proximity to the students they support can impede opportunities for the students with disabilities to engage in age-appropriate communication with their non-disabled peers or even lessen their access to rule-breaking or mischief. However, as noted in the discussion about friendships above, "adult" support or facilitation is often necessary to initiate relationships between, for example, students with and without disabilities in K-12 schooling contexts (Cuckle & Wilson, 2002; Evans & Meyer, 2001; Matheson et. al., 2007; Rossetti, 2011; Rossetti & Keenan, 2017; Turnbull, et. al., 2000). There also exists a substantial literature base documenting the role of support staff in research with individuals with IDD labels. As I evidenced in Chapter 5, my findings aligned with previous literature that characterized support staff as helpful in assisting individuals with IDD labels to participate in focus groups (Conder et. al., 2011; Ramcharan, et. al., 2004). However, in the data excerpts included in Chapter 5, as well as the instance noted above, questions and tensions arise when the presence and participation of support staff members alter how the students made meaning of the photographs they decided to share, and possibly the students' abilities to be seen (or to see themselves and their peers) as college students with all the accompanying social meaning this moniker carries. Within the focus group sessions conducted for this study, there are

not additional examples of how the presence of support staff may have affected the students'

access to developing reciprocal, age-appropriate relationships, namely because of my

methodological decision to ask that they remain outside. Thus, since college is a critical time for

identity development and social-emotional growth for young adults who attend, specifically with

regards to sexual identity (Arnett, 2015; Olmstead, Conrad & Anders, 2017), future research

invites the question of if, or to what extent, the presence of support staff affects how students

navigate social or intimate/sexual relationships, possibly for the first time (Allen, Husser, Stone

& Jordal, 2008; Olmstead, Conrad & Anders, 2017).

Uncomfortable Conversations About Inclusive Postsecondary Education

The findings discussed throughout this chapter have uncovered tensions between how my

participants understood and represented their college experiences and what a Disability Studies

reading of those experiences communicated. Perhaps the biggest tension arose when one student,

Victoria, shared photographs about her experience interacting with the CU women's basketball

team. As mentioned, CU athletic games, particularly basketball games, held a heightened

significance in the social lives of all CU students, including the AMP students. My participants

understood and articulated the high "status" ascribed to basketball games and the basketball

players. For example, during the data collection period Booker talked about the course in which

he was enrolled called "Religion and Sports," and so I asked:

KV: And so of course here, what would be the 'sports religion' here at CU?

Johnny: Basketball.

Billy: Basketball.

Booker: Basketball.

Many students were season ticket-holders and had grown up attending CU basketball games with

their families. In fact, Billy shared pictures with the group of the CU basketball players he often

referred to as "my guys," since he and Kevin, one of the Student-2-Student leaders, served as

managers of the team. Billy attended practices and sat on the team's bench during home games.

Some of the other participants were envious of Billy's managerial role, particularly Johnny who

lamented, "I wish I could like… help him… like, with the games. Like, with the basketball

team." During an early focus group session, Victoria shared a photograph of her with the CU

women's basketball team, taken after a recent home game. Victoria and her support person Holly

shared information about the circumstances surrounding the picture:

> Victoria: That's me…umm... hanging out with the basketball players.
>
> Holly (says excitedly): So, they (EF: the women's basketball players) came… it was like,
>
> her highlight of her night! She didn't know that it was going to happen… me and Kristen
>
> (EF: Victoria's peer partner) were kind of stirring this up…But she didn't *KNOW*! How
>
> did we get floor seats? (To Victoria).
>
> Victoria: Umm basically, they basically had…
>
> Holly (interrupts): Do you remember how we got floor seats?
>
> Victoria: Umm, tickets?
>
> Holly (Giggles): Well, Kristen asked if we could sit down there and watch her perform
>
> (EF: Kristen is a CU cheerleader), so we got to sit close. And then we had surprised
>
> Vicky with being able to see the team. So, one of the players, I have a picture of one of
>
> the players who had asked to take a picture with Vicky. And the team, we were standing
>
> around just hanging out and then the next thing you know, the team just comes out going,
>
> "Vicky! Vicky!" and they know her name, and it was pretty cool!
>
> KV: And so, you didn't know that was going to happen, it was a surprise?

Vicky: Yeah, I didn't know it was going to happen… I was like "whoa."

Holly: They asked her a couple questions, to get to know who she was…and it was like, a good half-hour, 45 minutes, we were standing on the court and they were just like, wanting to talk to Vicky! They invited Vicky to go practice with them, which was pretty cool. So when they come back from, you know, the tournament, she can go and practice with them!

The way Victoria and Holly relayed this experience communicated the celebrity-like status that the basketball players held on CU's campus. The other participants in the focus group session were similarly impressed, remarking how cool it was that Victoria was able to meet the basketball players and take pictures with them. What stands out to me is how, in Holly's telling, Victoria seemed to also hold a celebrity status to the players. When Holly noted that the basketball players "all knew her name," "asked her questions," and "wanted to take a picture with her," the implication is that they viewed Victoria as unique, or different from their other CU classmates who attended the games. I did not interview the basketball players for this study and thus do not know their motivations for asking Victoria to take pictures with them, nor is there data to evidence why they understood Victoria's presence as somehow novel. Holly's key role in facilitating this interaction likely set this specific tone, without which the players and Victoria might have related to each other in a different way. If Victoria attended the game with another support person or if Holly understood and carried out her role differently, Victoria's presence and participation may have looked quite different. However, the tension that a Disability Studies reading of these data highlights, depicts Victoria in tokenistic ways (Beckwith, Friedman & Conroy, 2016; Shakespeare, 1996). Multiple actors shared common, though unspoken, assumptions about disability that served to contextualize Victoria's specific experience at the

basketball game. Due to educational and social histories that have kept people with and without

disabilities in segregated spaces, it's not surprising that the traditionally-enrolled college students

on CU's basketball team might regard Victoria as someone deserving of special privileges such

as floor seats, post-game access, photos with the team, or invitations to watch their practices. The

shared, though unspoken, assumptions about people with intellectual disability labels as

deserving of special access, characterize at least this aspect of Victoria's college experience as

what Van der Klift and Kunc (1994) would label as "benevolent."[6] While Victoria was not

overtly discriminated against or excluded from accessing university sporting events, her presence

and participation was not the same as her same-age peers without disabilities. Holly's or

Kristen's motivations for planning this surprise for Victoria could, in fact, be reactions to their

knowledge of the marginalized and sometimes oppressive realities in which many people with

intellectual disability labels still live. Individuals who choose careers in disability services or

volunteer to be peer partners may harbor attitudes or beliefs about disability rooted in righting

perceived wrongs and see their work as motivated by good intentions (Van der Klift & Kunc,

1994).

In unpacking this instance and thinking about Billy's role as the manager of the men's

basketball team, there again exists an inevitable gray area—can Billy's experience be read in

similar ways? As noted above, Billy was not the only student manager of the men's basketball

team but he was the only one with a visible disability, and the only one profiled across various

media outlets from student film projects to campus and community news stories. Perhaps the

most salient questions involve how Billy is represented or how his participation is understood by

---

[6] In their chart about "Responses to Diversity," Van der Klift and Kunc (1994) locate benevolence on the same plane as tolerance, below their ultimate goals of valuing and belonging.

the larger campus community? I found it difficult to remain ambivalent about the optics of

Victoria and Billy's presence in these spaces, cognizant of the entrenched social and cultural

histories of individuals with intellectual disability labels, particularly Down syndrome, as

recipients of the non-disabled "gaze" (Garland-Thomson, 1997; Oliver, 1990). While the facts of

their participation are unremarkable—Victoria attended a women's basketball game and Billy

served as a student manager—the information that Holly relays ("They asked her questions about

herself!") and Billy's manager job highlighted across several media outlets (as mentioned he was

the subject of a feature story in the CU student newspaper, the local newspaper, and a film

student's class project), reveals what Garland-Thomas (1997) characterizes as the curiosity of the

non-disabled that can serve to "enfreak" and thus assert power over. Because the AMP program

was so new at the time of this study, how the larger community made meaning of the students'

membership in the campus culture likely had ramifications that extended beyond the individual

level. However, Billy and Victoria relayed these experiences as overwhelmingly positive. They

enjoyed the privileged access they were afforded and selected photographs from these

experiences to share during our focus group sessions. Though the purview of this analysis is not

to litigate if these kinds of experiences are ultimately harmful or beneficial, it does warrant

critical examination and questioning: what does it mean for inclusive postsecondary education if

students with IDD labels are afforded special access or privileges solely because of their

disability labels? In his analysis, Prohn (2014) highlighted a similar tension, eventually arriving

to a more cautionary conclusion, suggesting that for his participants whose college lives were

also highly supported and structured by the PSE program or other outside supports, "an acute

quality of life may have come at the expense of a future quality of life" (p. 174). It feels

admittedly uncomfortable to point out these instances in ways that straddle the fence between

being critical of the students' experiences and honoring the experiences as they were told to me. However, Van der Klift and Kunc (1994) highlight similar "good intentions" that continue to inform attitudes toward disability as merely something to "tolerate" rather than moving to what they understand as the ultimate goal of truly valuing disability diversity and engendering an authentic sense of belonging. They advocate that: "Genuine valuing of diversity will require further confrontation with the more subtle forms of discrimination (e.g. tolerance) and the courage to examine our own beliefs and practices as part of the process" (Van der Klift & Kunc, 1994, Responses to Diversity—From Marginalization to Valuing section, para. 17).

Chapter 7

Conclusion

In this dissertation, I investigated the college experiences of ten students with intellectual and developmental disability labels enrolled in an inclusive postsecondary education program over the course of one academic semester. Through a phenomenological, participatory study using student photographs as visual supports, the students and I discussed what college meant to them in weekly focus groups. Informed by methodological and theoretical frameworks of feminist theory in initial design, and Disability Studies throughout design, data collection, and analysis, I attempted to honor the students' experiences as they were told to me, allowing them to speak for themselves as the sole experts on their lives. For these students, college presented opportunities for forging new friendships, participating in campus social activities, navigating sometimes-challenging coursework and seeing themselves (or being seen by others) as the same as everyone else. Methodological findings exposed the limits of seemingly inclusive qualitative methods, sometimes reproducing ableist notions of communication, participation, or performance for individuals with IDD labels participating in academic studies (Milner & Frawley, 2018). Additionally, a Disability Studies reading of the students' experiences told new and often contradictory stories that highlighted tensions around postsecondary education program involvement, reciprocal friendships, staff support roles, tokenism, benevolence and intellectual disability identity. Therefore, this concluding chapter will include the following: 1) A brief summary of key findings; 2) Participatory research realities; 3) Limitations and; 4) Implications and future research directions.

Summary of Key Findings

Chapters 4 and 5 presented findings about the college experiences of students with IDD labels as well as findings about doing qualitative research with this unique population, while Chapter 6 discussed those findings through a Disability Studies lens. In Chapter 4, the students reported that, for them, participating in the Alma Mater Program (AMP) at Central University (CU) meant attending various social events and activities organized by AMP program staff and volunteer peer partners from the Student-2-Student program. Most of the students who participated in this study shared photographs from these social events including: seasonal recreation activities such as apple picking, ice skating, skiing and swimming, group trips to the mall or to watch the local hockey team play, movie nights at the off-campus apartments of their Student-2-Student peer leaders, and attending myriad university sporting events, namely, basketball games. The data evidenced the significant role played by both the AMP program staff and the traditionally-enrolled students who volunteered as Student-2-Student peer partners. Jim, for example, often lauded the AMP program's role in facilitating these events, while Johnny lamented at the prospect of losing access to these social opportunities when he graduates from the program.

Also discussed in Chapter 4, the AMP students documented and shared photographs of their friend networks, largely comprised of other AMP students and the traditionally-enrolled students who volunteered for the Student-2-Student program. The AMP students characterized their relationships with the Student-2-Student peer partners differently, with Chris, Jim and Johnny discussing their sometimes not-so-positive relationships, and Victoria and Shannon reporting higher levels of satisfaction. Perhaps most interestingly, Shannon articulated an ambiguous understanding of how to define her relationship with the students who participated in

the Student-2-Student program: labeling them as "peer partners" who were assigned to her by the AMP program staff felt incompatible with Shannon's sense that they were "more like my friends." Shannon recognized the complexity inherent in her relationships that were facilitated by the AMP program, seeking to make what she understood as an important distinction between peer partners and friends—the latter figuring in Shannon's world as possessing a different, and perhaps deeper, connection. Additionally, the AMP students who participated in this study often shared photos that depicted groups comprised only of other AMP students. Though they exhibited a strong program cohesiveness, they were aware that not everyone was part of the AMP program "in crowd." For example, Chris and Kerianne did not often show up in group photographs, preferring to talk about their lives outside of the context of the AMP program. Chris highlighted his job working in the kitchen at the local zoo while Kerianne boasted a strong relationship with her extended family, frequently sharing pictures taken at family gatherings.

Though the students did not often bring classes into the focus group discussion space, I proposed "academic life" as a first photo topic around which to take pictures, correctly anticipating that the discussions would otherwise center on social lives and relationships. For the students, their experiences in classes were generally positive, though the lack of instructor communication and fast pace of instruction sometimes presented barriers to access and participation. Academic mentors (i.e. individuals who were paid to support the students in class) were described as key components to their perceived levels of success and enjoyment or, for Jim in particular, understood as partly responsible for his poor performance. Most significantly, many of the students expressed frustration with one aspect of the AMP program—namely, that though they communicated to me how they "do all the same work" as traditionally-enrolled CU students, the requirement that they audit their courses without earning credit and without earning

a degree seemed unfair. Johnny, Chris and Jim anticipated experiencing difficulties in securing employment opportunities without "real degrees."

Lastly, Chapter 4 presented findings about how the students who participated in this study defined college. For them, college was a time that was wholly different from high school in terms of friendships, classes, and not only how others viewed them but how they viewed themselves. Shannon highlighted how she had come out of her shell since starting college, Billy reported that he could finally just be himself, while Johnny talked about how participating in the AMP program meant that he could abandon his identity as someone "in special ed" and what he understood as the low expectations and ridicule that often accompanied that identity. The students who participated in this study reported their college experiences as largely positive, highlighting friendships as the key to assuaging initial nerves and enhancing their membership and belonging within the larger CU campus community.

In Chapter 5, I presented findings that specifically addressed methodological themes. Because individuals with IDD labels have historically been characterized as a "difficult" population to include in qualitative research, I paid close attention to the process as well as the product. Adhering to the political, democratic ideals of Disability Studies research and feminist research, I sought to design and implement a study that was participatory and that followed my participants' leads, privileging their voices however they manifested. Later in this chapter I discuss my relative level of "success" in delivering on my participatory aims. The findings in Chapter 5 highlighted themes and tensions around collecting data and the role of the researcher in this inquiry. In coding the transcripts generated from the focus group recordings, I traced a theme I termed "seemingly non-sequiturs"—that is, many of the students who participated in this study often contributed to group discussions in unexpected ways, at unexpected times, or veered

from the topic at hand. Rather than align with traditionally deficit-based understandings of this theme as connected to participants' communicative or cognitive "challenges," I proposed alternative explanations for what might be going on throughout these data. Namely, by investigating the larger context surrounding these non-sequitur instances, I found that several of my participants were in fact contributing to group discussions, they just needed more time to organize their thinking and presentation or communication of their contributions. The pace of the focus group discussions was often such that, for example, Victoria or Johnny, would add to a topic that had been covered a few minutes prior. Additionally, as documented in Chapter 4's findings, Chris and Kerianne sometimes offered comments that highlighted things in their lives that they valued and wanted to share. Because they were not part of the AMP program "in group," their statements sometimes read as "seemingly non-sequiturs" because they chose not to or did not have access to attending many of the AMP social events.

Also in Chapter 5, I discussed findings about the role of support, both between staff members and their clients and between the students themselves. Consistent with previous research about the role of support staff in the lives of individuals with IDD labels (both in schooling contexts and in research contexts), the presence of the staff members had the potential to facilitate or hinder the students' participation. While they sometimes asked guiding questions to scaffold their clients' access to group discussions, there were also instances when the staff members dominated the focus group space, either talking over the students or even changing the meaning that the students made of the pictures they shared. I also found that the students served as natural supports for each other during the data collection sessions. By building off each other's ideas, troubleshooting technology access, or asking each other questions, I saw the potential of these natural supports and made intentional methodological decisions to foster and

extend opportunities for them.

Finally, Chapter 5 presented findings about my role as the researcher throughout the data collection process. I drew from methodological journal entries that documented my musings around how to maintain the participatory goals I set out to achieve, trying to avoid being seen by the students as the one "in charge" of the research. My data collection approach evolved throughout veering from its initial PAR-informed design to instead always follow the leads of my participants, aiming to scaffold their participation and access to the photo-taking and discussion processes. Ultimately, the students continued to interact with me as their teacher, often only sharing pieces of information directly with me, asking me direct questions, and otherwise adhering to ingrained expectations of "good" or "smart" students to which they had likely been acculturated throughout their educational careers (Hatt, 2011).

Chapter 6 took a deeper dive into the findings discussed in Chapters 4 and 5, using the theoretical lens of Disability Studies to see what new stories the data communicated. I discussed tensions around the AMP program's significant role in structuring positive social experiences for their students, drawing on previous studies that raise questions about the nature and kind of program support in students' current and future qualities of living. I tried to understand the students' friendship networks in conversation with previous literature on the topic, broaching issues of reciprocity and authenticity of relationships that often "look different" than those between typically-enrolled students. I also attempted to shine a light on the inevitable shadows in the data—how, by and large, my participants did not describe themselves as individuals with disability identities but rather focused on how their new lives as college students allowed them to see themselves and be seen as the same as everyone else. Extending the findings from the previous chapter, I proposed alternative explanations for how the students participated in the

group discussions, assigning meaning and function to the "seemingly non-sequitur" comments in hopes of constructing their communicative competence. I zoomed in on a uniquely illustrative example of how the presence of support staff had the potential to not only change the meaning the students made of their photographs, but also served to limit their ability to be seen as sexual actors, comparable to their non-disabled peers. Lastly, I wrestled with the question of if the students' college experiences could be labeled "inclusive" when findings sometimes illustrated how members of the larger CU campus community interacted with the AMP students in tokenistic or benevolent ways.

Participatory Research Realities

My personal and professional commitments to authentic participation and collaboration of self-advocates in research about their lives informed the way I approached my study's design and choice of methodology. I initially decided to align with a Participatory Action Research (PAR) framework because of PAR's commitments to reflection and tangible action (Kemmis & McTaggert, 2000; Paeiwonsky, 2014). Even as I anticipated that the project would shift throughout, I found that the structure of my initial PAR design was not as flexible as I had hoped. My own reflective journaling helped me to pay close attention to the process and thus informed the changes I made, abandoning the requisite components of PAR studies that ask participants to engage more fully in the analysis process while ultimately landing on a tangible outcome or actionable step to affect change in their worlds. While I was marginally successful in achieving my "participatory" aims, I offer that this study can be more aptly categorized as "inclusive," though not without some ambivalence as I discuss below.

In Chapter 2, I reviewed literature about participatory research methods specifically for participants with intellectual and developmental disability labels. To reiterate, Kemmis &

McTaggert (2003) note that participatory research methods exist on a continuum, with participant involvement varying in depth and breadth. Distinguishing them from "emancipatory" research paradigms that fully relinquish the reins of ownership to the participants, Ramcharan, Grant and Flynn (2004) identify three specific processes associated with "participatory" studies:

> …A research question being brought to the attention of disabled people or being identified by disabled people themselves; disabled people and researchers working together to achieve a collective analysis; and alliances formed between disabled people, researchers, and others to see to make change following the research (p. 92).

Regarding the first point, scholars engaged in participatory studies with similar populations acknowledge a challenge I faced since this study was conducted as a dissertation that required prior approval. That is, similar to what they call "contracted research" (Conder et. al, 2011; Ramcharan, Grant & Flynn 2004), the norms and processes of my doctoral program required me to propose this study and have it approved by a committee. For many academic researchers, they also report generating ideas for studies and then later "inviting" individuals with intellectual disability labels into the process (Grant & Flynn, 1994; Minkes, Townsley, Weston & Williams, 1995; Northway, 1998; Ramcharan, Grant & Flynn, 2004). Thus, my participants did not identify my research questions nor did they propose its initial design. I attempted to navigate these tensions in several ways. First, the research questions I developed were intentionally broad and open-ended. My hope was that simply asking what my participants' college experiences were, rather than asking them to rate their relative levels of satisfaction with said experiences, or asking other more-focused questions, would serve to maintain a balance of power between them and me (Garcia-Iriarte, Kramer, Kramer & Hammel, 2009). Additionally, by designing a study informed by theoretical and methodological commitments to the Disability

Studies ideologies of presumption of competence and consultation, I closely followed the students' leads throughout the data collection process and made methodological changes accordingly. As I described in Chapter 3, I abandoned the initially-proposed "photo quest" structure—collectively deciding on a common theme for the week and then having students take photos that represented that theme—and instead offered that the students share one or several of the photos they deemed as most salient from the past week. They often mined their social media accounts and elected to bring up a picture they had already decided to share with their virtual communities. I rationalized that if the students did not decide where the study began, they would dictate where it ended up. However, I did not conduct member checks with the participants in my study, which rightly deserves acknowledgment and rationalization. Upon proposing this study, I anticipated that after I transcribed, coded and analyzed my data, I would set-up either face-to-face meetings with my participants or Skype/FaceTime conversations to chat about how I represented my findings to garner their input and feedback. I ultimately decided against doing this for a few reasons. First, these data captured a very specific moment in time for the students in this study. Many were first-year students in the AMP program whose lives and worlds were steadily changing and this dissertation lived very much within one academic semester. By the start of the next school year, students' social networks and social relationships changed, sometimes their living situations changed (two participants moved into the CU dorms), and some moved from taking classes to participating in internships. Scholarship about college student identity development supported my hunch that young people enrolled in four-year colleges and universities experience fast and significant changes in a short period of time across multiple domains including: developing competence, navigating emotions, establishing independence, and discovering or honing their sense of self (Allen, Husser, Stone & Jordal, 2008; Chickering,

1969; Olmstead, Conrad & Anders, 2017; Thieke, 1994). By the time I had organized findings ready to share with them, I anticipated that revisiting experiences from over a year ago would add a whole new, reminiscent dimension to the study that I thought would distract from my initial design—aiming to capture a snapshot of the college experiences of these students in that very specific time and place. Thus, I trusted that my built-in, responsive and iterative methodological approach to data collection ensured that my participants' voices and experiences were rendered and represented faithfully. Below, I discuss possibilities for future research that does embark on a more reflective path and propose what might be gained from this approach.

I achieved the second participatory research objective of "collective analysis" in part, though not in full. As I stated in Chapter 3, I decided to utilize participant photographs not as data for me to analyze about what their college experiences were, but as visual supports to facilitate the focus group discussions and serve as discussion starters or discussion organizers to get at their understandings of their own experiences. My hope was to conduct more explicit analysis of the photographs the students brought to the group every week by facilitating group coding exercises where the students would caption their pictures and then organize similar captions into groups. Because this did not occur in great depth, I sought to realize a more "collective analysis" by framing and presenting my findings in purposeful ways. Namely, I presented data to illustrate those findings not as mine but as the students'. In fact, in initial drafts of my data chapters, I sought to represent the students' experiences without what I perceived to be editorializing. In trying to guard against obfuscating my participants' voices, I over-corrected and in effect ended up scrubbing my own voice from my discussion. In the end, our "collective analysis" was achieved more in the co-existence of the findings. I attempted to honor the meaning my participants made of their own experiences as college students whilst also utilizing

the theoretical framework available and accessible to me as a Disability Studies scholar to probe the data in search of new or different understandings.

Regarding the final criterion of affecting change after completion of the research, this piece is more difficult to determine. However, the students who agreed to participate in this study did so with the knowledge that the AMP director would have access to the data that were collected, analyzed and disseminated. While this fact had the potential to (and likely did) alter how some participants described their college experiences (i.e. some might have tempered their discussion contributions if they knew the director might know what was said), it also had the potential to inform future directions of the program. Though evaluation activities are required of all TPSID grantees (Grigal, et. al., 2014), those activities might not get at student experiences in the same way or with the same level of detail. Feedback forms that depend on written communication skills might limit the input opportunities of students with more complex needs, that my photo-based approach served to mitigate. Additionally, it's possible that as someone not affiliated with The Center for Inclusive Higher Education or the AMP program, the students felt more comfortable being critical of their experiences and offering suggestions for improvements. Therefore, if this study's findings inspire changes or future directions of AMP programming, this aim of participatory research will be met. However, the absence of the "A" in Participatory Action Research is what ultimately caused this work to no longer fit its initial PAR moniker. Though the students created a slideshow from the pictures they took throughout the semester, this was not a product or action that then informed a subsequent "cycle" of the research process. The Implications and Future Research section proposes new questions for future scholarship seeking to implement PAR methodologies.

As I noted above, feelings of ambivalence linger when considering if my study was not

only participatory, but "inclusive." Drawing from Walmsely and Johnson (2003) and Nind (2011, 2014), Milner and Frawley (2018) document the trend across disability research towards more inclusive methods as the logical next step for scholars who adhere to social model understandings of disability. They explain:

> Consistent with the assumption that "disability" is not intrinsically embodied, but rather locatable within the array of institutional barriers that prevent full and active participation, disabled people's exclusion from the research academy came to be viewed as yet another kind of socially constructed absence, resolvable by dismantling methodological barriers that separated disabled people from the privileged (non-disabled) enclaves of knowledge production and dissemination (Oliver, 1990, 1992) (Milner & Frawley, 2018, p. 2).

Thus, my aim was to "dismantle methodological barriers" by designing and implementing a data collection environment to facilitate the participation of individuals that have been systematically excluded from the academy, in a study, incidentally, *about* their very presence in the academy. However, Milner and Frawley (2018) perfectly articulate the ironies and, arguably, hypocrisies, with which I've had to wrestle in that the participation requirements of theoretically "inclusive" methods, often continue to exclude the "harder to reach voices" (p. 4). The "missing voices" are those individuals "whose subjectivities are communicated beyond the ordinary lexicon" (Milner & Frawley, 2018, p. 4). I interpret this to mean that for individuals with intellectual disability labels whose communication, movement, sensory, or performance norms fall outside the realm of "typical," simply claiming to "include their voices," is not only insufficient, it may in fact reproduce the ableist conventions that excluded them from the academy and from academic research in the first place. Milner and Frawley's (2018) assertion

further illuminates my findings discussed in Chapter 5. For example, the finding around

"seemingly non-sequiturs," and the finding that the students seemed to interact with me as a

teacher or authority figure, exposed the shortcomings of how I designed and ultimately

implemented the focus group discussions. While using photographs as visual supports mitigated

some of the limitations of data collection that was based primarily on verbal group discussions,

my data collection procedures still fell within the realm of more traditional qualitative methods. I

ended up creating what Milner and Frawley (2018) term an "assimilative research space" where

the supposedly "inclusive" research methods I employed served to train, support or educate my

participants in ways "that approximate us" (p. 10). That is, the didactic nature of my facilitation

approach and my eventual role as teacher or authority figure meant that I unwittingly tried to

train my participants to perform in the research process in non-disabled ways, though I did

actively work in supporting them to do so. Additionally, Institutional Review Board conventions

required me to include specific training components in both the informed consent process and in

introducing photography as a data collection method. I facilitated discussions with the

participants about what constitutes research, what it meant to participate in my study, and how to

request permission to take someone's photograph. Though intended to safeguard against

repeating the history of individuals with intellectual disability labels being taken advantage of or

abused in the name of research, the institutional structures of the academy reinforced and

extended these "assimilative spaces" in which the product of my data collection was ultimately

text-based, benefitting the students who were most adept at producing communication in this

way. Milner and Frawley (2018) acknowledge the ultimate hypocrisy of their own and, they

argue, all academic research that espouses inclusive ideals:

> Not only are people with a learning disability still waiting to hear their unedited

unexplained voices within the biblitheca of the academy, those who argue that they have a place are required to demonstrate nimbleness within the minefield of critical disability theory and a grasp of problematized constructs like subjectification and narrative authenticity. As a consequence, academics, by self-created self, find themselves with little option but to draw on the othering and completely inaccessible vocabularies of Foucault and Deleuze and Goodley and Lather and now ironically, Milner and Frawley (p. 13).

Put simply: to be accepted into academic circles and published in academic journals, "inclusive" researchers are conditioned to report the findings of their "inclusive" studies using language and vocabulary that is inaccessible to individuals with intellectual disability labels, effectively "re-othering" the intended beneficiaries of this work. I acknowledge that the language in this dissertation is no exception. However, the end-of-semester celebration where Jim debuted the photos the group had taken and compiled them and others in a slideshow set to music, was one way the AMP students who participated in the study were able to access its findings and share them with others. My first research question asked how students with IDD labels described and represented their college experiences and thus the photographs that the group took inside and outside of this study served to answer this question in an accessible way. In my discussion of implications for future research beginning on page 199, I suggest a way forward for researchers seeking to design and implement inclusive, participatory methodologies to garner and represent the experiences of individuals with intellectual and developmental disability labels.

Limitations

It's almost inevitable that as soon as I take the first bite of a meal I've just prepared, I think about how I'm going to make it differently the next time—I should have pickled the onions

for longer, I should have used sea bass and not tilapia. The challenge for me has always been

finding a balance between appreciating something I've produced for what it is and keeping an

eye towards the future in a constructive, not-too-self-deprecating way. Therefore, in discussing

the limitations of this study, I acknowledge some of the structural or logistical realities as well as

the decisions that, had I made a different choice, might have helped to better garner and represent

the students' experiences.

Because I designed this study to capture a specific moment in time—the data collection

occurred over the course of one academic semester—there were limited opportunities to

document the students' evolving experiences and perspectives. Higher education literature notes

that, for young adults, the nature of college is such that their social, academic and social-

emotional lives change rapidly over the course of their tenures (Allen, Husser, Stone & Jordal,

2008; Olmstead, Conrad & Anders, 2017). Thus, drawing larger conclusions about what college

is for students with IDD labels from data collected over such a relatively short period of time,

risks essentializing the themes discussed, or applying them to the totality of their college lives.

Particularly because most of my participants were in their first full years in the AMP program,

the data collected largely represents students at the start of their college careers. Almost two

years after collecting data, I keep up with some of my participants and see updates on their lives

via their social media accounts. Already I can see that some of their social networks have

widened or shifted, some are experiencing living on campus for the first time, some have broken

apart from what was previously a cohesive group, while some are graduating and navigating

their lives after the AMP program. Additionally, I wish I had conducted more participant

observations to generate additional field notes. So much of my analysis was gleaned from how

students talked about their photographs and their experiences that I would have liked to generate

a fuller picture of these experiences. Specifically, attending classes with students or tagging along at more AMP program events would have flushed out my overall data set and provided additional context for the photo discussions.

Another limitation of this study was that, due to confidentiality priorities, I decided not to include students' photographs in the dissertation itself. Though I have attempted to describe them faithfully, readers would benefit from seeing the actual photographic data the students collected. As noted previously, warranted and necessary IRB conventions added layers of structural complexity to this work that, in turn, highlighted interesting tensions, particularly around issues of informed consent for populations deemed "vulnerable," such as individuals with intellectual disability labels. I could have made the decision to ask the students if they wanted to waive confidentiality all together, and participate in the study with their identities known to the readers. Though it's difficult to admit, I was already so apprehensive about garnering informed consent from my participants and ensuring that it was authentic, that I thought adding this layer of ethical complexity was too much to navigate. That is, knowing the power dynamics already at play between me and the students (an older, teacher-like figure who is asking them to participate in a study) I was dubious if the students would have a deep appreciation of what waiving confidentiality would really mean. It's worth noting that I would feel this way about traditionally-enrolled college students as well, perhaps hinting at some latent deficit-based assumptions I harbor about all "millennials." Though again, I was confident that the design of the study aligned with theoretical and methodological principles that themselves reflected commitments to full participation and consultation, I could not be sure how this work would be taken up by others, and didn't want to put the students at risk of experiencing unanticipated adverse effects of sharing their stories. I considered how waiving confidentiality might affect

what the students elected to share in the focus group settings, and rationalized that maintaining confidentiality was the best decision in the current context.

Perhaps due to the age difference between me and many of the participants, I underestimated how much of their social interactions "live" in virtual spaces. The students' social media accounts were not included as sources of data for this study but my findings may have benefitted from including them. Including social media data would have allowed me to access new and different information with regards to how the students represented themselves: what pictures they elected to share, how they communicated information about their identities, what was important to them, or where they spent their time and with whom. For students who sometimes struggled to participate in the focus group discussions or for whom the picture-taking tasks were burdensome, including social media data may have mitigated these challenges.

Finally, I designed this study to explicitly privilege and center the voices and experiences of college students with IDD labels. I assumed an epistemological orientation that informed the methodology I employed, ultimately deciding to only include the students as informants. Because of a political commitment to what I understood as trying to counteract previous qualitative traditions that have marginalized or excluded disabled voices, I may have over-corrected. That is, my findings about friendships, about the students' identities in the AMP program and at CU, or about the role of the AMP program itself, were limited in their scope since I only represented the students' understandings. Integrating more or varied perspectives from different stakeholders (e.g. traditionally-enrolled peer partners, support staff, AMP program staff, or parents) would have painted a more detailed account of not only what the students' experiences were, but how to define the contours and conflicts of inclusive postsecondary education. Though there were a few opportunities to interact with the students individually,

either before or after our focus group meetings, online, or at social events, I wish I had built in one-on-one interviews or conversations with my participants. Knowing that not all people are comfortable sharing their thoughts in a group setting, this was a missed opportunity for me to account for their communicative preferences in an additional way.

Implications and Future Research Directions

As postsecondary education programs continue to emerge across the country for students with intellectual and developmental disability labels, there is also an emergence of this liminal space in which the now more than 250 programs live. Within this space are programs that range from those who cobble together a college-like experience for one or two students to those that adhere to specific philosophical and structural models that are implemented for annual cohorts of fifty or more students. Therefore, it behooves program faculty, administrators and staff to ask themselves: What *are* they experiences of the students who come through our doors and, knowing that our students may receive or express information in non-traditional ways, how can we get at those experiences? As presented throughout this dissertation, the college experiences of the students in this study are characterized by initial apprehension, hard work, new friendships, and fervent school spirit. Though the purview of this study was not to compare participants' experiences with those of typically-enrolled college students, higher education literature suggest that these experiences are not unique to students with intellectual and developmental disability labels (Freeman, Anderman & Jensen, 2010; Paul & Kelleher, 1995; Pittman & Richmond, 2010; Wilcox, Winn & Fyvie-Gauld, 2006). However, this inquiry generates host of new questions to consider when developing and implementing scholarship within the field of inclusive postsecondary education.

Consistent with the extant literature, it's as-of-yet unclear how "inclusive" these students'

college experiences are, or who even decides and defines those parameters. The field of inclusive postsecondary education necessitates future scholarship that operationalizes "inclusion" and then seeks to document it. Researchers have several tools available to assist in this endeavor including standards, benchmarks and quality indicators developed by Think College (Grigal, Hart, & Weir, 2011), model accreditation standards for TPSIDs released by the National Coordinating Center Accreditation Workgroup (2016), and metrics such as Booth and Ainscow's "Index for Inclusion" (2002). Though these tools offer important places to start to standardize the field's definition of what makes a college program "inclusive," they will only tell part of the story. They may miss those little moments of joy, satisfaction or apprehension that inevitably occur within the expanding worlds of all students at this pivotal time in their lives. Therefore, I propose that future studies also utilize inclusive, qualitative approaches to investigating the college experiences of students with IDD labels to continue to privilege their previously-unaccessed or silenced voices and propose ways to value data that is not only language or text-based. In an age where technology can be a powerfully-equalizing and potentially "normalizing" force, students with intellectual and developmental disability labels leave their social media "footprints" in much the same ways as their typical peers. Though I did not include the students' social media accounts as sources of data for this study, many of my participants brought their social media photos and comments into the focus group space. It would be interesting to design a study that specifically looks at Facebook, Instagram, Twitter, Snapchat or other yet-to-be-realized platforms as tools of inclusion or exclusion. Additionally, for students for whom verbal communication is limited or simply not their preferred mode of expression, mining social media data may offer insights into how they understand or represent their identities as college students or as individuals with disabilities.

Additionally, since we know that students with intellectual and developmental disability labels are largely educated in substantially separate settings in their K-12 schooling, I wonder how this factors into their ability to access postsecondary education? If so, how? To extend my study, or others like it, it would be interesting to collect data about the placement histories of students with IDD labels that do attend college and see if any trends emerge. It's cynical to think that alternative pathway college programs are simply extending special education by three or four years. And yet these questions and others like it, persist. To reiterate Hart's (2013) assertion regarding her vision for inclusive postsecondary education, she says: "We're not talking about modifying curriculum or any course content. It's not bringing special education to higher education. It's about providing the supports and accommodations that will assist the student in being successful and participating in that class, and learning" (Think College, 2013). And so, it begs the question: among the 269 postsecondary education programs for students with IDD labels across the country, is Hart's claim realized? Findings from my study highlight the efforts the AMP program and the Student-2-Student program undertook to do just this, namely regarding social experiences. My data illustrated the significant and important role of the structures and practices of the AMP program in providing the supports and accommodations for students to integrate into the campus community. Future studies might look to academics, specifically, and ask questions about how students with IDD labels are accessing college course content. Relatedly, larger, philosophical questions about the nature and purpose of postsecondary education arise when considering my participants' understandings that they will not earn what they understood as meaningful credentials upon completion of their programs. If students with IDD labels do not receive modified coursework, but instead participate in highly-structured or supported classes with the necessary accommodations and related services, then inclusive PSE

programs should investigate what meaningful credentials might look like. Since almost two-thirds of high school graduates go on to postsecondary education rather than undertaking apprenticeships or immediately entering the workforce, there are arguments that suggest the value, meaning, or purpose of a bachelor's degree is changing (Bureau of Labor Statistics, 2015). Trends document that rather than linear paths from college to professions, many students instead view this time as opportunities for self-exploration, self-actualization or even self-reinvention (Levine & Dean, 2012). Of over 60,000 college students surveyed, respondents cited their reasons for going to college as including: enhanced independence and freedom, to experience university life and have fun, to figure out precisely what they want to do in the future, because college is a "natural progression" from high school and because everyone else they know also went to college (Levine & Dean, 2012). Thus, if the purpose or function of undergraduate programs is shifting away from professional or vocational training, does that shift have the potential to open doors for populations of students who, a generation ago, might not have considered college a possibility at all? My sense is that this shift has already occurred, or is in-the-midst of occurring, but that the institution of higher education and its perhaps antiquated view of itself as "exclusive" may draw the line at a "free appropriate [college] education" for all (they'll certainly draw the line at "free"). However, this study raises an important question with which all institutions must contend: if higher education has not only an economic responsibility but a social responsibility to create opportunities for young people to access curiosity, thus graduating an informed, engaged, responsible citizenry (McArthur, 2011), then shouldn't all young people be granted that access?

The findings from this study also highlighted the critical role that friendships played in the lives of my participants. However, as noted in my discussion of limitations, the relationships

described in my data are presented only from the perspective of the AMP students, and not the peer partners who volunteered for the Student-2-Student program. In thinking about new directions for research about friendships, there exists an inherent stickiness with which future studies must contend. Because this study and others suggest issues with authenticity or reciprocity between friends with and without disabilities, researchers are tasked with asking difficult questions that risk uncovering difficult answers. What does it mean if the friendships to which students with IDD labels have access are largely only with other students IDD labels, or with traditionally-enrolled students who volunteer for facilitated friendship programs? Is it ableist to assign normative notions of friendship to these relationships, or is it necessary? What are the experiences of peer partners who volunteer for these kinds of programs and do they sense the tensions that arose in my findings? Are they reciprocal and authentic? Who decides? Does it matter?

This dissertation has interesting and at-the-same-time messy implications about issues of segregation vs. congregation, marginalization vs. affinity, and stigma vs. identity for college students with IDD labels. As seen throughout the Deaf cultural community (Gesser, 2005, Fischer & Lane, 1993; Padden & Humphries, 1988; 2005) and increasingly within the Autistic cultural community (Rosqvist, Brownlow, & O'Dell, 2015; Sinclair, 2010; Woodfield, 2016), individuals who identify based upon disability label or shared communication, sensory, or mobility norms, often seek out spaces where they can enact these norms without needing to perform for the larger able-bodied world. As documented in my findings, the students often shared pictures of themselves as a distinct cohort, sometimes only socializing or congregating with other AMP students. While this finding could be read as college reproducing segregated educational and social spaces for individuals with IDD labels, other disability cultural models

offer alternative explanations or interpretations of how these spaces are created—i.e. are these groups just special education classrooms or segregated recreational opportunities translated into college settings, or do these groups more closely resemble first year college student learning communities or affinity groups that form based on other dimensions of diversity? Future research is needed that investigates the meaning of intellectual disability identity and asks individuals how they come to claim it or why they choose to resist it? While asking these disability-focused questions would logically have uncovered a whole new world of data about how college students with IDD labels define themselves and how they understand this facet of their identities, it's also possible that these findings would risk, as discussed in the previous chapter, further essentializing these students as Disabled people first, and perhaps most, whether or not that's how they viewed themselves.

As I ponder these and other lines of inquiry, what is clear is the value and necessity of not only integrating, but centering the voices of students with IDD labels in future scholarship, policy and practice. Learning from and with the intended beneficiaries of this work is a moral and practical imperative that requires the same kind of creative, boundary-crossing thinking that first considered college as not only a possibility but a reality for students with intellectual and developmental disability labels. Thus, this dissertation has far-reaching implications for future research with participants with IDD labels, specifically for research with participatory or inclusive aims. Additionally, this study highlights key challenges and warranted critiques of Participatory Action Research (PAR) frameworks and participants with IDD labels or other traditionally-marginalized groups. Most salient for this work, critics of PAR highlight the inherent messiness of scholarship within institutions of higher education that seek to claim the PAR moniker—namely that achieving the ideals of "empowerment through inclusive

participation" and "impact through concrete and collection action" may remain one-sided, disproportionally benefitting the doctoral candidate or faculty member whose gains (i.e. formal credentials, peer-reviewed publications, tenure and promotion) are most tangible and most valued in a neoliberal culture (Lake & Wendland, 2018, p. 20). Burns (2007) notes that the "facilitators" of PAR studies are positioned within "learning systems" in ways that invariably give them "considerable power in steering, prioritizing, and even interpreting" what goes on in data colletion and analysis (p. 168). Ironically, it was the PAR design framework that I felt necessitated too much structure and thus too much power. This study was conceived and amended to always center the previously-marginalized voices of individuals with IDD labels and follow their leads and, in this quest, it abandoned its PAR label and lives instead in a more liminal space. Future PAR scholarship within higher education might consider how to negotiate the blurred institutional roles and expectations associated with who is the researcher, who are the participants or informants, who analyzes the data, who benefits from its dessimination, or, as Burns (2007) aptly highlights: "many research ethics committees assert that material generated prior to the formal start date of the research cannot be used... yeah if the researcher if part of the research then it is impossible for them to not bring in their past, because their whole history is part of the research" (p. 165).

I see scholars such as Nind (2011, 2014), Milner and Frawley (2018), Paeiwonsky (2011, 2014) and Woodfield (2016) as most helpful in charting a methodological course forward. Woven throughout all of their scholarship are shared commitments that should serve as bedrocks for inclusive, participatory research with individuals with disabilities that may manifest in complex communication and support needs: 1) Flexibility and creativity in data collection methods employed; 2) Constructing participation based on multiple modes of receptive and

expressive communication; 3) Prioritizing consultation, transparency and ownership of the inquiry; 4) Reframing "academic" expectations and insisting on accessibility of language and content; and 5) Allowing ample and significant time for study design, data collection and analysis, and presentation and dissemination of findings. Without establishing these principles as paramount and non-negotiable, the academy will continue to propagate the ableist structures and practices it purports to want to dismantle and remain stagnant in its own hypocrisy.

As more students with IDD labels are afforded access to postsecondary education, it's not only the academy broadly that must wrestle with supporting their membership, or researchers that are tasked with garnering their experiences, but also the field of Disability Studies that is compelled to contend with the findings discussed therein. As I wrote Chapter 6, I observed how often Disability Studies proved insufficient in capturing a faithful interpretation of my findings. Though I realize that's not the ultimate goal of any theoretical framework, the field's insufficiency was most evident to me as it seemed to persist in offering new understandings of my participants' experiences as inherently bad, or potentially harmful. At the time of this writing, I know that I don't yet have the words to describe what I think is going on, but my findings confirmed an overall sense of dis-ease I have been feeling about the field in general. Apart from my frustrations with the ethereal and inaccessible language used by much of the "mainstream" Disability Studies scholars and the palpable irony in writing about intellectual disability in ways that exclude the very subjects about which they're writing, it sometimes feels like there's not enough space for ambiguity in this discipline. For example, during my first year of doctoral training, I conducted an interview study with other Disability Studies doctoral students and recent graduates as part of a qualitative research course. I wanted to know how my peers defined the field and understood what Disability Studies "is," what it should do, and how

they defined this boundary-drawing concept of those who "get it" and those who don't. Namely, there seemed to be a shared, though unspoken, understanding of the values and behaviors that constitute a Disability Studies "insider," someone who "gets" disability, and someone who does not. The people I interviewed understood someone who "gets it" as affirming disability identity, sharing a politics of disability pride, and believing in the social model while rejecting special education and segregated, manufactured social worlds. As I discussed towards the end of Chapter 6, I've wrestled with tone or intent throughout writing this dissertation, trying to resolve a tension I can't seem to shake: isn't it contradictory to Disability Studies politics, values and commitments to suggest that my participants are somehow "wrong" in their assessments of their college experiences? And yet, if Billy wants to be the manager of the men's basketball team, and Victoria wants to feel honored to take pictures with the women's basketball team, and Shannon wants to abandon the term "peer partner," and Booker chooses not to identify as a person with a disability, and the AMP students want to congregate as a cohort, then does Disability Studies understand these as authentic "choices"? Can Disability Studies negotiate what I see as a rather thorny irony between honoring the agency of these students to claim their experiences as positive ones, while also inciting productive conversations about if these experiences are enough? Even as we acknowledge that there are multiple ways to articulate and enact Disability Studies politics and practices, and multiple access points via which to participate in the work of this discipline, is there ever a tipping point at which accepting ambiguity bleeds into rationalizing and thus legitimizing the status quo? I think it's a necessary reminder to all theoreticians that the goal should be to focus the critical eye of Disability Studies not on individuals, but on structures and systems that interact to create social realities in which people have access to certain narratives and certain understandings of their worlds. For example, the students in this study illustrated

understandings of how the structures and systems at CU and within the AMP program ultimately shaped their lives now and in the future. Johnny and Jim recognized that the event organizing role of the AMP staff and Student-to-Student peer partners facilitated their access to participating in social activities and thus developing friendships. Chris acknowledged that credential he and his AMP peers would earn might not afford him access to post-school employment opportunities comparable to his non-AMP peers. Shannon described how the limited availability of academic support staff meant that Abby, who was "not really my peer partner but more like my friend," "had to" serve in this role, potentially complicating what she understood as otherwise a reciprocal, authentic friendship. As Broderick and Kasa-Hendrickson (2006) offer:

> Qualitative inquiry in Disability Studies, therefore, generally seeks to understand the nature of the social, cultural, and political construct of disability by turning its gaze not exclusively upon the individuals who experience and are labeled with disabilities; rather it focuses more broadly upon the social, cultural, and political contexts and interactions within which notions of what it means to be "disabled'' are enacted (p. 176).

By the same token, it's important to remind practitioners working in inclusive postsecondary education settings to pay closer attention to the aforementioned contexts and interactions and focus their efforts accordingly. I believe there's a way to maintain a certain level of restlessness that reminds us all we're not yet "there," while also acknowledging and valuing the current social realities in which our students live, work and learn.

I've kept up with many of the students who participated in this study from a distance— largely via their social media accounts and AMP program updates. They've also kept up with me, congratulating me on the birth of my son, Hugo, and "liking" the endless pictures I post of him on Facebook. Though the data collection for this study did not extend past one academic

semester, what is clear is that the students' lives are changing, and changing fast. Some are now living on campus in the dorms or their own apartments, taking on leadership roles within the Student-2-Student program, forging new relationships and ending old ones, and participating in internships. A few have graduated from the AMP program and are pursing full-time employment. They continue to take pictures of themselves and their friends, adding to their seemingly never-ending virtual scrapbooks. Booker in particular has documented dozens, perhaps hundreds of selfies taken in front of locations across CU's campus and, when sharing them with the group, read aloud the sort-of social media "refrain" that often accompanied these selfies, showcasing the pride he felt as a "dragon" in his new life as a college student. During one focus group session, he recited these hashtags: "#RememberMyDragonLife, #CU2020, #CUNation, #LetsGetIt, #RememberMyName. Those are for me in my CU life. In my CU life I am happy." I was always struck at how often all the students took moments to reflect upon how fulfilled they felt in their "new" lives at CU. Throughout the semester, they emanated this sense of almost wistful gratitude as they shared photos of themselves walking across the quad, in front of their favorite campus building, at a winning basketball game (or even at a losing one), or smiling with a group of other AMP students and their peer partners. They are here, and they are happy.

Appendix A

Invitation to Participate

Dear (insert name),

You are invited to participate in a research project where YOU get to share your thoughts and experiences about being in college!

Who? **Any Alma Mater Program[7] students who likes to take pictures (or wants to learn!) and share stories about being in college.**

When? **Tuesday mornings from 10:00AM-11:00AM.**

Where? **In the AMP conference room located at 123 Kensington Hall.**

Is it required? **No it's not, it's totally optional.**

Why? **You are a unique group of students and we want to know what you think about being in college. Your voices and your stories are important! You get to learn about doing research! It will be fun!**

Have questions? Come learn more about the project or contact Katherine Vroman.

Katherine's contact information: kmvroman@syr.edu or 617-697-2251 (cell phone)

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[7] Names have been changed to maintain confidentiality.

Appendix B

Photography Ethics Training Outline

Introduction: What is research?

- Facilitated discussion about definition of research – participants will co-generate ideas of what research means and examples of research with which they are familiar
    - Discussion of data and types of data
    - Photographs as data

What are ethics?

- Facilitated discussion about definition of ethics
    - Examples of ethics in general and ethics in research
- Group brainstorm about why ethics are important in research?

Ethics in research: Asking for photo consent

- Who do you need to ask for consent?
    - Photo "subjects" as the "star" or "stars" of the photograph vs. photo "objects"
- Introduction to Photo Release Form and its components

Role-playing Activities: All participants will participate in role-playing activities as the

"photographer."

- Scenario 1: Asking to take a person's photo and he/she agrees
    - Conversation starters
    - Describing the study
    - Subject agrees
    - Asking for signature on photo release form – asking age of potential photo subject

- Scenario 2: Asking to take a person's photo and he/she does not agree
    - Conversation starters
    - Describing the study
    - Subject does not agree
    - Conversation closers

- Scenario 3: Asking someone else to take your picture
    - Conversation starters
    - Showing someone how to use your camera/phone/iPad ("Push this button")
    - Describing what you want included in the phone

Questions and Discussion

- What do you do with the signed photo release forms?
- System for storing photographs and sharing with the group
- Other?

Group "field trip"

- Participants walk around building or outside to practice with researcher assistance

Appendix C

Consent/Assent Form [8]

College Experiences of Students with Intellectual and Developmental Disabilities
Study Consent and Assent Form

> If you are the legally authorized representative for someone who might participate this study, your permission is required. When the word "you" appears in this consent from, it refers to the person for whom you are legally authorized to give consent.

You are invited to be in a research study about the college experiences of students with intellectual and developmental disabilities. You should go over this form with someone you trust: a parent, guardian, friend, staff member or mentor. If you have a legal guardian, that person will need to read this form and sign it as well.

Katherine Vroman and Beth Myers are in charge of this study. Katherine is a graduate student at Syracuse University in the School of Education and Beth is the director of the Taishoff Center. Beth is working with Katherine to provide help and advice throughout this process.

You are invited to **share your experiences** about what it's like to be a college student.

Why are we doing this study?[9]

Since there are not very many programs like Inclusive U., we want to learn about things like:

- **What college is like** for students with intellectual and developmental disabilities, specifically:

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[8] This form was adapted and used with permission from Dr. Katherine McDonald.
[9] Icons made by Freepik from www.flaticon.com

- o A typical day in college, your friends, your classes, where you live, and what you do for fun.
- We also want to **learn about your experiences participating in this research study** and **some of your personal information**. Since Inclusive U. has already collected this information, we would ask Bud Buckhout to share this information with us, if it's ok. The personal information we are interested in is:
  - o Your name, gender, age, race/ethnicity, what kind of high school program you attended, and what kind of diploma you received.

If you decide to participate in this study, what will you be asked to do?

You and the other students who decide to participate will **meet with Katherine for one hour, for eight mornings during the semester**. **The meeting will only last for one hour**.

You will be asked to **take pictures** about different parts of your college experience and **share those pictures with the other students** in the group, as well as with Katherine.

You will **share information about the pictures** you took and discuss things like: who or what is in the picture, where the picture was taken, how the picture makes you feel, why you took the picture and why you decided to share the picture with the group. As a group, we will write descriptions or captions of the pictures that everyone takes.

At the end of the semester, you will have **the option to share your favorite pictures** with your friends and family. This is optional and not a required part of the project. If you do not want to share your pictures with your friends and family, you do not have to.

Katherine **will audio record the group discussions** so she can remember what everyone says. Katherine and Beth will be the only ones with access to these recordings.

We will keep them in a locked drawer in a locked office, or on Katherine's computer that is password protected and will be erased after 5 years.

At the end of the semester, you will be asked to **meet one-on-one with Katherine for between 1 and 2 hours** and talk about what it was like to participate in the study. She will ask you things like: what did you like about it, what did you not like about it, what could be done differently

next time, what were your favorite pictures you took and why? Katherine will audio record these conversations to remember what you said.

What if I don't want to answer a specific question? What if I don't want to share all of my pictures?

You can decide not to participate in specific discussions or stop and leave the group. You can decide you answer some questions about your pictures, but not all of them. **It is your decision**. You can only share the pictures you want to. You do not need to share all the pictures you take.

Will other people know I am participating in this project? Will you share what I say with other people?

Katherine and Beth will keep what you say as confidential as possible (private or secret) with the exception of certain information that we must report for legal or ethical reasons (if someone breaks the law or does something against the research rules), such as situations of abuse (if

someone hurts you), and/or if you plan to hurt yourself or others.

If we need to report something that is against the law, is against the research rules, or if we learn that someone has hurt you, has hurt others, or if you plan to hurt yourself or others, we will need to tell the police, someone in charge at Syracuse University like Bud Buckhout, and/or your parents/guardians.

Because there will be multiple people in the group discussions, **we can't guarantee total confidentiality** because other people will see the photos you take and hear what you say. You might feel uncomfortable or embarrassed sharing some things, or hearing what other people share. **You can decide what you want to share,** it is up to you.

To be sure that all of the information is kept as confidential as possible, Katherine will:
- Give you a different name so people are less likely to know that you participated in this project.

- Give Syracuse University a different name and give Inclusive U. a different name.

- Keep all of the project's information on a safe computer with a password, locked in an office where only Beth and Katherine are able to access.

- Keep what you say as private and secret as possible so other people will not know what you have shared.

- Delete the audio recordings after they are transferred to a secure file on a secure computer and then delete those files after 5 years.

What are good things that might happen if you participate in this project?

You might **like sharing your experiences and opinions** about what it's like to be a college student and feel good about **helping us and other people learn**.

If you choose to, **you may have the opportunity to present with Beth and Katherine at conferences**, or help us write an article for publication, after the project is completed. If you decide to attend a conference with us, we would help each other with the presentation and we would pay for your travel, your food and your hotel costs. You do not have to present at conferences or help us write an article to participate in the project, it is not required.

What are bad things that might happen?

Katherine and Beth **do not expect anything bad** to happen to you from participating in the study.

It is possible that **you might feel uncomfortable or embarrassed** thinking about or sharing difficult experiences you've had in college. Or, you might feel frustrated if you are not sure how to answer a question, or have problems as you take pictures and share them with the group. As a reminder, participation is not required, but if you decide to participate, **we will support you to have a positive experience.**

What will happen if you decide NOT to participate in this study?

Nothing! No one will be upset if you choose not to participate. It's not required of your program.

It is your right to decide.

What should you do now?

Ask questions.

Think about it.

Talk to a friend, family member, or peer mentor.

Decide if you want to participate in the study.

If you would like to participate in the study:

If you have questions about the study, contact:
Katherine Vroman
Syracuse University
617-697-2251
kmvroman@syr.edu

If you have questions or problems about the study that you do not want to ask Katherine or Beth, contact:
Institutional Review Board (IRB)
Syracuse University
315-443-3013
orip@syr.edu

Beth Meyers
Syracuse University
315-443-128

You may stop your participation in this study at any time, without anything bad happening. By signing this form, you are agreeing to participate in this study and are letting us know you are age 18 years or older.

I agree to let Beth and Katherine collect some of my personal information from Inclusive U.

Yes ☐   No ☐

_____
Participant Name   Participant Signature   Date

_____
Guardian/Legal Representative Name   Guardian/Legal Representative Signature   Date
(if applicable)

_____
Researcher Name   Researcher Signature   Date

If you have a legal guardian, you will be given three copies of this form. Please sign one copy of this form and bring it in person to Beth Myers or Katherine Vroman. Please keep the other two copies for you and your legal guardian.

If you do not have a legal guardian, you will be given two copies of this form. Please sign one copy of this form and bring it in person to Beth Myers or Katherine Vroman. Please keep the other copy for yourself.

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benevolence-friendship-and-the-politics-of-help

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Past, present and futures. New York, NY: Jessica Kingsley.

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Wehmeyer, M. L. (2005). Self-determination and individuals with severe disabilities: Re-examining meanings and misinterpretations. *Research & Practice for Persons with Severe Disabilities, 30*(3), 111-120.

Wehmeyer, M. L., & Garner, N. W. (2003). The impact of personal characteristics of people with intellectual and developmental disability on self-determination and autonomous functioning. *Journal of Applied Research in Intellectual Disabilities*, 16, 255-265.

Wehmeyer, M.L & Abery, B.H. (2013). Self-Determination and Choice. *Intellectual and Developmental Disabilities*, *51*(5), 399-411.

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implementing participatory action research. Archives of Physical Medicine and

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severe learning disabilities who have difficulty developing personal relationships.

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0with%20Disabilities.pdf

Woodfield, Casey Lee, "Blazing trails, being us: A narrative inquiry with five high school

students with autism who type to communicate" (2016). *Dissertations - ALL*. 461.

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Zarb, G. (1992). On the road to Damascus: First steps towards changing the relations of disability research production. *Disability & Society, 7*(2), 125-138.

Curriculum Vitae

Katherine Marie Jorgensen Vroman
1114 Radcliffe Street
Bristol, Pennsylvania
(617) 697-2251
kathvro@gmail.com

EDUCATION

Ph.D. Candidate, Cultural Foundations of Education
School of Education Syracuse University, Syracuse, NY
Dissertation (Working title): "'And then you can prove them wrong': The College
Experiences of Students with Intellectual and Developmental Disability Labels"
Chair: Beth A. Myers, PhD
Committee members: Christine Ashby, PhD, Michael Gill, PhD
Expected completion: June 2019

C.A.S. Disability Studies
School of Education Syracuse University, Syracuse, NY
August 2019

Master's in Education: International Educational Development, *magna cum laude*
School of Education Boston University, Boston, MA
May 2010
Master's Thesis: **"**Principles for Change: An Inclusive Education Professional
Development Initiative for School Leaders"

B.A., Classical Civilization and Women's Studies, *magna cum laude*
College of Arts and Sciences Boston University, Boston, MA
May 2004

PROFESSIONAL CREDENTIALS and CERTIFICATIONS

Teaching English as a Foreign Language Certification
International TEFL Certificate (ITC)
Barcelona, Spain
August 2004

RESEARCH AND TEACHING EXPERIENCE

Graduate Assistant, Boston University School of Education – Boston Public Schools
Collaborative Office and Department of Special Education
Boston University, Boston, MA
September 2009 – May 2010

Graduate Research Assistant, The Institute on Communication and Inclusion
Syracuse University, Syracuse, NY
September 2012 – September 2017

Graduate Teaching Assistant, Introduction to Qualitative Research Methods
 Syracuse University, Syracuse, NY
 September 2013 – July 2014

Interim Campaign Advisor, DREAM: Disability Rights Education and Mentoring
 Syracuse University, Syracuse, NY
 September 2013-January 2014

Graduate Assistant, Taishoff Center for Inclusive Higher Education
 Syracuse University, Syracuse, NY
 January 2014 – September 2017

Institutional Ethnography Research Team: "Minding the Gap": The Textually Mediated Experience of Institutional Accessibility
 Syracuse University and SUNY Purchase
 January 2014-December 2015

Deafness and Disability, Adjunct Professor
 Syracuse University, Syracuse, NY
 Summer 2016

Issues and Policies in Inclusive Education: Race and Disability, Adjunct Professor
 Montclair State University, Montclair, NJ
 Summer 2017

Social and Legal Foundations of Special Education, Adjunct Professor
 The College of New Jersey, Ewing, NJ
 Fall 2017 – present

Teaching Students with Significant Disabilities, Adjunct Professor
 The College of New Jersey, Ewing, NJ
 Spring 2019

PUBLICATIONS

Singer, S., Vroman, K. (2018). Deaf: A Culturally-Sustaining Philosophy for Deaf Education. In D. Ford (Ed.) *Key Words in Radical Philosophy of Education,* Koninklijke Brill Publishers, Amsterdam.

Hamilton, C., Vroman, K., and Myers, B. (February 2018). "In my SU life, I am happy": The Social Media Representations of a First-Year Student in Inclusive Higher Education. *TASH Connections*.

Vroman, K. and Elder, B. (2016). "The first day of school was the worst day of my life": Best Practices in Inclusive Education for Refugee Youth with Disabilities. In: *Enacting Change From Within: Disability Studies Meets Teaching and Teacher Preparation,* Christine Ashby and Meaghan Cosier (Eds.): Peter Lang Publishing.

Ashby, C., Jung, E., Orsati, F., Reuttemann, C. & Vroman, K. (2015). "Wishing to go it alone": The complicated interplay of independence, interdependence and agency. *Disability & Society,* 30:10, 1474-1489.

Vroman, K. & Woodfield, C. (in press). At the Borders of Inclusion and Integrazione: Narrating Tensions in and through Disability Studies **.** *Italian Journal of Disability Studies* .

Singer, S. & Vroman, K. (out for review). Researcher Positionality in Inclusive and Emancipatory Research, *Disability & Society.*

Ashby, C. Woodfield. C., Dickens, B., Vroman, K., Heath, K. (in preparation). Mapping communicative support: Documentation of augmentative and alternative communication services in IEPs. *Teaching Exceptional Children.*

Ashby, C., Woodfield, C., Heath, K., Vroman, K. (in preparation). Fostering Communication Through Physical Activity: Fit Families and The Cycle of Communication. *Good Autism Practice.*

Ashby, C. Jung, E., Heath, K., Vroman, K., Woodfield, C. (in preparation). iPads for Communication: The role of practice in developing communication through typing.

CONFERENCE PRESENTATIONS
Rappaport, M, Dougherty, K., Holmes, T. & Vroman, K. (2011, March). *I am Norm: Youth-Run Advocacy for Inclusion* (Workshop). Girls Scouts of the USA Keys to Leadership Conference, Washington, D.C.

Liebowitz, C. & Vroman, K. (2011, May). *Celebrate Inclusion: Youth Advocacy and Activism* (Keynote). Celebrate Inclusion: New York City Public Schools, New York, NY.

Holzthum, N., Goldsmith, D., Brown, T. & Vroman, K. (2011, August). *I am Norm: Youth-Driven Activism* (Keynote). 13th Annual Autism Summer Institute at the Institute on Disability, Nashua, NH.

Vroman, K. Holzthum, N., Habib, D. & Carroll, K. (2011, August). *I am Norm: School-Based Activism for Youth with and without Disabilities* (Workshop). APEX Summer Leadership Institute, Bartlett, NH.

Dougherty, K., Holmes, T. & Vroman, K. (2011, December). *TASH Youth Leadership Summit* (Workshop). TASH Annual Conference, Atlanta, GA.

Orsati, F., Reuttemann, C., Ashby, C., Jung, E. & Vroman, K. (2013, June). *A world of difference: Analyzing the development of independence of individuals with disabilities in typing to communicate* (Research presentation). Society for Disability Studies Annual Conference, Orlando, FL.

Vroman, K. (2013, June). *Post-Colonial Feminist Disability Studies : A Transformative Framework* (Paper presentation). Society for Disability Studies , Orlando, FL.

Ashby, C., Orsati, F., Reutemann, C., Jung, E. Vroman, K., & Chadwick, M. (2013, July). *A world of difference: Analyzing the development of independence of individuals with disabilities in typing to communicate* (Research presentation). Institute for Communication and Inclusion Annual Summer Institute, Syracuse, NY.

Shallish, L., Taylor, A. & Vroman, K. (2013, October). *"Nothing about us without us" doesn't recognize borders: New Approaches to Disability Theorizing in Education* (Panel, Discussant: Nirmala Erevelles). American Society for Educational Studies, Baltimore, MD.

Vroman, K. and Singer, S. (2013, December*). Communication diversity in higher education and a self-determination model of academic accommodation* (Paper presentation). TASH Annual Conference, Chicago, IL.

Jung, E., Orsati, F., Ashby, C., Reuttemann, C., & Vroman, K. (2013, December). *Comparative study of linguistic features of people with autism and their facilitators* (Research poster). TASH Annual Conference, Chicago, IL.

Vroman, K. (2014, March). *Mapping the Disability Diaspora* (Research panel). 7th Annual Equity and Social Justice Conference, Syracuse, NY.

Fialka-Feldman, M., Singer, S. & Vroman, K. (2014, March). *Recognizing value in diverse scholarly writing: Questioning the status quo* (Research panel). 7th Annual Equity and Social Justice Conference, Syracuse, NY.

Ashby, C., Orsati, F., Reutemann, C., Jung, E. Vroman, K. (2014, April). *"Wishing to go it alone": The complicated interplay of independence, interdependence and agency* (Research panel). American Educational Research Association (AERA) Annual Conference, Philadelphia, PA.

Ashby, C., Woodfield, C., Jung, E. Vroman, K., Nichiporuk, K. (2014, December). *iPad for Communication: A Case Study of iPad App Training for the Development of Independent Communication* (Research presentation). TASH Annual Conference, Washington, D.C.

Vroman, K., Woodfield, C. & Ashby, C. (2015, April). *Communication Under Fire.* (Research Presentation). Disability Studies in Education conference. Chicago, IL.

Vroman, K. (2015, April). *Constructing Knowledge-Makers: Representation Of Individuals With Complex Communication Needs In Academic Conference Culture,* individual paper as part of the larger panel*: Typing and Talking Back: Challenging Prevailing Discourses of Research With Persons With Complex Communication Needs* (Research panel in collaboration with Ashby, Jung, Nichiporuk and Woodfield). American Educational Research Association (AERA) Annual Conference, Chicago, IL

Vroman, K., Woodfield, C., Ashby, C. & Dickens, B. (2015, December). *The Right to Respectful Communication Support: Developing a Code of Ethics.* (Research presentation). TASH Annual Conference, Portland, OR.

Ashby, C., Woodfield, C., Dickens, B. & Vroman, K. (2015, December). *Communication [Still] Under Fire: New Directions in Research and Practice for Individuals who Type to Communicate* (Research presentation). TASH Annual Conference, Portland, OR.

Vroman, K., Woodfield, C., Dickens, B., Ashby, C. (2016, April). *An Unspoken Code: Collaboratively Developed Ethics for Communication Support Professionals* (Research presentation). American Educational Research Association (AERA) Annual Conference, Washington, D.C.

Vroman, K. (2016, April). *Research with non-speaking participants: Searching for new directions in qualitative methodologies in Disability Studies* (Research presentation). American Educational Research Association (AERA) Annual Conference, Washington, D.C.

Woodfield, C., Vroman, K., & Ashby, C. (2016, June). *The Freshman Year: Experiences of College Students who Type to Communicate* (Research presentation). Disability Studies in Education conference, Des Moines, IA.

Vroman, K. & Myers, B. (2016, December). Beyond Emails: Developing a Plan for Distance Collaboration Among Postsecondary Education Professionals. State of Art Conference on Postsecondary Education and Individuals with Intellectual Disabilities, Fairfax, VA.

Ashby, C., Woodfield, C. Heath, K. Dickens, B. & Vroman, K. (2016, December.) Mapping Communicative Support: Documentation of augmentative and alternative communication services in IEPs (Research presentation). TASH Annual Conference, St. Louis, MO.

Singer, S. & Vroman, K. (January 2017). Emancipatory research: Fulfilling its promise? 29th Annual Ethnographic and Qualitative Research Conference (EQRC). Las Vegas, NV.

UNIVERSITY SERVICE
President, Beyond Compliance Coordinating Committee
    Syracuse University, Syracuse, NY
    May 2013 – May 2015

Board Member, Disability Cultural Center
    Syracuse University, Syracuse, NY
    January 2013 – May 2015

Search Committee Member: ADA Coordinator
    Syracuse University, Syracuse, NY
    May 2013-December 2013

Search Committee Member: ADA Coordinator
    Syracuse University, Syracuse, NY
    January 2015 – May 2015

Reviewer, *Issues in Teacher Education*
    September 2018 - present

Reviewer, *Critical Education*
    Special Series: Ableism in the Academy: A Series about Disability Oppression and
    Resistance in Higher Education
    October 2018 - present

INVITED TALKS

Vroman, K. (February 2015). Disability in Romantic Relationships and Access to Sexuality.
    Syracuse University

Vroman, K. (February 2015). Writing In-Between, Living In-Between: A celebration of Minnie
    Bruce Pratt. Syracuse University.

Vroman, K. (March 2015). Preaching to the Choir: Academic Silos and The Challenge of
    Disability Studies . Syracuse University.

Vroman, K. (April 2015). The Social Construction of Disability. Syracuse University.

Vroman, K. (November 2015). Culture, Communication and Ethics: *"Not being able to speak is
    not the same as not having anything to say."* Upstate Medical University.

Singer, S. & Vroman, K. (October 2017). The Deaf Bicultural Family. Towson University.

Vroman, K. (October 2017, September 2018). Writing inclusive, standards-based IEPs. The
    College of New Jersey.

RELATED PROFESSIONAL EXPERIENCE
**Project Director, *CommonWell*: Boston University/DotWell Campus-Community
Partnership**
Dorchester, MA
January 2009 – January 2012
- Coordinate recruiting, training, and curriculum development for
    CommonWell: a transdisciplinary service learning project for Boston
    University graduate students

- Facilitate weekly learning modules in social justice areas such as Preventative Law, Fiscal Health, Cultural Competency, Coordinated Social Service Delivery, Educational Advocacy and Campus-Community Partnerships.

Campaign Project Manager, *I am Norm*
January 2011 - January 2012
- Coordinate activities of national youth inclusion campaign for youth with and without disabilities
- Facilitate development of youth keynote presentation content and coordinate conference logistics
- Develop and maintain operational partnerships with collaborating organizations
- Initiate grant writing, fundraising and development
- Develop and produce campaign educational materials for national dissemination

Special Projects Assistant, *Think College*, **Institute on Community Inclusion at UMass Boston**
Boston, MA
January 2012 - January 2013
- Work with Massachusetts UCEDD on various projects in support of postsecondary education access for students with intellectual and developmental disabilities
- Manage content and format of Think College's Literature and Training and Technical Assistance databases to increase usability and relevance
- Assist principal investigators as needed with literature reviews, data analysis and social media

Inclusive Education Consultant, *Cheryl M. Jorgensen Consulting, LLC*
December 2015 – present
- Consult with families, educational teams, related service providers and self-advocates regarding the inclusion of individuals with disabilities in school and society
- Conduct on-site and virtual meetings with IEP teams, families and related service providers
- Provide individualized, evidenced-based recommendations for the adoption and implementation of inclusive policies and practices
- Focus on communication access, equity and participation

GRANT WRITING
Petroff, J., Panscofar, N., Vroman, K., Singer, S. (2017). (unfunded). *The New Jersey Wellness MAPS Project*. U.S. Department of Health and Human Services Administration for Community Living, National Institute on Disability, Independent Living, and Rehabilitation Research: *HHS-2017-ACL-NIDILRR-IFDV-019*

LANGUAGE SKILLS
Fluent in American Sign Language, Basic Italian and Spanish