

HARRINGTON, LALENJA GIDDENS, Ph.D. (Un)restricting the Imagination: Community Engaged Research Involving College Students with Intellectual Disabilities and Implications on Scholarship, Postsecondary Programming and Pedagogy in Higher Education. (2017)
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This dissertation explores the intersection of community engaged research and arts-based methodologies involving students with Intellectual Disabilities (ID) on a college campus, with broader theoretical connections related to disability identity and day to day practice that impacts access to higher education. This intersection, presented as a nexus of “visionary pragmatism” in the words of Patricia Hill Collins (1996) represents a coming together of theory/vision and the practical strategies that students with “unruly body/minds” must use to navigate the world on their own terms.

Using thematic and poetic analysis of person centered planning documents and student interviews, the research circle (consisting of students, faculty, community members and program staff) sought to answer two research questions: 1) what do students with ID consider personal growth as it relates to being in college, and 2) how do students perceive the supports needed to achieve their desired goals. The community engaged approach encouraged power sharing within the research circle, including students with ID as co-researchers in collective data collection and analysis, and as peer interviewers. In alignment with Universal Design and feedback from scholars with ID regarding accessible formatting, literature, discussion and analysis are presented in a multimodal format that includes graphics and poetry. Themes from the data reflect perceptions of college as a path to self-realization and self-determination (critical consciousness), valued roles, careers and financial stability, interdependence, social justice and inclusion.

(UN)RESTRICTING THE IMAGINATION: COMMUNITY ENGAGED RESEARCH
INVOLVING COLLEGE STUDENTS WITH INTELLECTUAL DISABILITIES
AND IMPLICATIONS ON SCHOLARSHIP, POSTSECONDARY
PROGRAMMING AND PEDAGOGY IN
HIGHER EDUCATION

by

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APPROVAL PAGE

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CHAPTER I

INTRODUCTION

The college experience is comprised of a wide array of possible experiences; some social, some academic, and some employment. These experiences will likewise be unique for every individual who attends college. There is not one right way to do it. A student's experience will reflect their personal needs and goals. Some students will take many classes, while others choose to go part-time. Some students seek skills that will lead to employment; others may want to explore a new area of personal interest. It is in this aspect that college environments provide an array of experiences that most students with intellectual disabilities are not afforded during their tenure in public school; the chance to explore, define, and redefine personal goals related to adult learning, employment, and social connections (Grigal & Hart, 2010, xiii).

When I think about the history of education in the United States I am reminded of the ever-changing colors and patterns of a chameleon. A slippery, opportunistic creature that ensures its survival by alternating between forms in response to the hegemonic demands of its environment. As such, we have seen the field move through shifts, trends and times of appropriation, adaptation, innovation and transformation. In its contemporary form, we see the ways in which systems of schooling overtly and covertly reflect cultural and economic pressures to commodify, where product is valued over intrinsic motivations for equitable learning. It is in this environment that students who do not fit cookie

cutter teaching practices and resist notions of education as production struggle to claim valued space within classrooms.

The educational system in the United States has a poor history of engaging these “unruly bodies and minds” in classrooms in all settings, and ensuring access to opportunities to explore, define, and redefine themselves in the university setting like their matriculating peers . I have borrowed this term “unruly” from the work of Nirmala Erevelles (2000), who rejects the Foucauldian concept of body as something that is “docile... that may be transformed and improved” (p. 25) and embraces the concept of body as actively able. This resistance to passivity is important, as it speaks to agency and to body/minds that resist being normalized, fixed, or ruled, and represents a power in unruliness that I seek to celebrate in this research.

Unruliness in education can be observed/explored through a number of lenses and/or directions. Within this construct of unruly and for the purposes of this study, I am choosing to magnify the identity of students with intellectual disabilities (ID)- not with the goal of privileging this identity over others, but as a way to explore how the lived experience of disability informs the larger discussion about unruliness in education. Expanding on this idea, as well as the definition above, I use the term here specifically to refer to those bodies and minds that do not conform to dominant expectations of ideal studenthood, reinforced by dominant ideology, be it due to race, ethnicity, ability, sexuality, religion or other

identities that are experienced from the margins. In essence, within the framework of education, unruly can be applied to a plurality of bodies and minds that question the ways in which equality and meritocracy are evaluated as they relate to economic and social relationships/identities (Sadovnik, 2009).

I am in agreement with Siebers (2008) who frames disability as a positive identity, that insists “on the pertinence of disability to the human condition, on the value of disability as a form of diversity, and on the power of disability as a critical concept for thinking about human identity in general” (p. 3). The goal of this dissertation, as I work to stand in solidarity with students with ID, is to help facilitate scholarly writing and research engagement that centers student voice and magnifies the lived experiences of those with ID in higher education. Its purpose is to challenge the idea that “ability is the ideological baseline by which humanness is determined,” and where it is determined that “the lesser the ability, the lesser the human being” (Siebers, 2008, p. 318).

In my ten years as the academic director for a four year certificate program for college students with intellectual disabilities, I have watched the students in my program come up against barrier after barrier, just to have the opportunity to be included and valued on their own campus. Their commitment to pushing on ideas of normalcy and ruliness is what motivates me as a researcher, professional, activist and as a person. I offer the following two vignettes to further encapsulate my “why” for doing this doctoral research.

Vignette 1-Nothing About Us Without Us

At a staff meeting in the spring of this year, one of the advisors in our program, Ryan, shared a frustrating experience during an on-line training on health services for people with ID that he attended. Training participants were asked to engage in an on-line activity, where they provided one word answers to the question, what comes to your mind when you think about students with intellectual disabilities in college? This training was designed to illuminate the perspectives/voices of people with disabilities receiving supports, yet the majority of the training activities were facilitated by professionals, and the trainers were professionals who did not identify as disabled.

Ryan shared his distress as answers scrolled across the screen, including words like, limitations, retarded, difficult to understand, unlucky, innocence, challenged, group home, adaptations, silly, trouble, disability, treatment, special needs, mental disorder, difference, unable, vulnerable, and the list goes on. The list was peppered with “affirming” words here and there, but by far the majority of the words were negative and/or patronizing. The irony of this situation did not escape any of us sitting at the table, and clearly illustrates the silencing and the type of deficit thinking that people with disabilities have and continue to encounter and resist in this climate of normalization -- a perfect example of the marginalization and discounting of personhood that sparked the clarion call of the disability community in the 70’s, nothing about us without us (Upias, 1972).

Greg's cloud (figure 2) is much more in line with what students in our program have described as outcomes that they are looking for in college. I would argue that the difference between the two clouds is a reflection of the state of the majority of contemporary scholarship concerning students with ID-not in their own words. Docherty et al. (2006), a collective of disabled scholars, argue this beautifully in the following passage,

We wanted to write an article in our own words. We think it is important that people get learning disabled people's point of view. Instead of listening to the lies from people in day services and places like that. We wanted to do an article like this, putting stuff down in writing about what we feel like, about what it's like for people who are learning disabled, what it's like to get to get bullied time and time again... Things have changed; the world has turned now. It's time to stop it always being the professionals doing everything. We want people to listen to us; listen to us and learn from us. We've seen tons and tons of reports about learning disability and they've all been done by people from organizations like BILD (British Institution of Learning Disabilities). There's lots of articles too, but most of the articles are written by professionals who think they know all about learning disability and it's time they included what we've got to say and what other learning disabled people have got to say, not just the professionals' and experts' views. Other disabled people are doing research and writing as well-- that's good, but only if they don't use big words. There's a lot of disabled writers and researchers like Mike Higgins from BCODP (British Council of Disabled People) and Mike Oliver but there's not a lot of writing from learning disabled people (Docherty et al., 2006, p.433)

I am particularly sensitive to the tension that arises when disabled authors and scholars are not included in research and scholarship that is about them and my role as a non-disabled scholar. The desire to make space for a better balance of voice and perspective is a foundational element of my research.

Vignette 2- Presuming Competence

“Danial” just graduated from UNCG with a certificate in Integrative Community Studies. When he entered as a first-year student, as his guardian, his mother was very involved in any and all decision making about his life, including his day to day schedule. In North Carolina, guardianship is defined as

a legal relationship in which someone (the guardian) is authorized by the clerk of superior court to be substitute decision maker for an incompetent adult (the ward). Incompetence is determined in a court proceeding and means an adult is unable to manage his own affairs, or is unable to make important decisions (NCDHHS, 2016).

Per these rules, Danial was effectively determined to be incapable of making decisions about his own life.

Over his four years in the program, Danial began to take on more and more responsibility for decision making and as he began to believe in his own capabilities, his parents began to see him in a new light, as a competent adult. Upon graduation, Danial, with support from his parents, petitioned for restoration of his rights, using life planning documentation that he developed in his college program. The courts granted the restoration, presuming Danial to be competent as Douglas Biklen (2005) would say, as a “thinking, feeling person who is capable” (p.73). Grigal and Hart (2010) speak to the significance of access to college in this process when they say, “The purpose of exposing students with intellectual disabilities to PSE is to provide them, for perhaps the first time in their

lives, the expectation that they CAN learn after leaving high school and the opportunity to CHOOSE to learn” (p. xv).

In a recent article, Greg said very much the same thing when asked about why college was important to him, “A lot of people don’t give us a chance” he said, but UNCG and this program, “they actually believe we can do something” (Hibbard, 2016). In Biklen’s (2005) collection of narratives by young people with autism, self-advocate Richard Attfield says, “In all my years at school I had not before felt as if I was part of some bigger perspective, as if what I thought was of significance. I was given recognition for my ability at college, not penalized for being disabled” (Biklen, 2005, p. 229). These statements by young folks with ID, like this poem below, provide a counterpoint to the story of Danial’s journey,

People say, ‘you can’t’ all the time.
You can’t get a job.
You can’t get married.
You can’t have a baby.
You can’t have your own house.
You can’t go out unless you’re with someone else.
You can’t get on a university course.
You can’t have a normal life.
But now *we can* and people need to learn that we can (Docherty et al., 2006, p.435).

Greg, Attfield and Docherty et al. are making a call for the “presumption of competence,” a foundational concept for this research.

Before moving forward, I think it important to highlight a number of other concepts that undergird my position and this work. The next section will clarify

concepts for the reader, including unrestricted imagination, postsecondary education, models of disability, inclusion, and disability “naming”, before I delve into other theoretical and methodological discussion.

Terms-Unrestricted Imagination

Each of the vignettes provided earlier speaks to the need to unrestrict our collective imaginations regarding the capabilities of folks with ID. Alisdair MacIntyre (1999) a moral philosopher who contends that disability is a much neglected element of philosophical discourse in academia, and challenges restrictions that limit access for disabled folk in education, citing the need for an “unrestricted imagination” which is “necessary to move beyond the constrained and impoverished view of disability held by many in our society” (p. x). He asserts that inadequate education has denied students with disabilities the right to ‘imagine alternative possibilities” (MacIntyre, 1999, p. 75).

I have found MacIntyre’s concepts of unrestricted imagination and alternative possibilities to be instructive ones for the purposes of our research. The array of possibilities for young adults with ID/DD beyond high school has been negligible at worst and limited at best. Students with disabilities have struggled to “claim space, voice and power to disrupt the normative ideals of the social world that has historically ignored them” (Erevelles, 2009, p.71), and the PSE movement, supported by federal legislation in the form of the Reauthorization of the Higher Education Opportunity Act of 2008, has come about as a direct response to a grassroots calling to challenge that invisibility

and unrestrict the collective imagination related to disability (Grigal, Hart & Weir, 2012). In that vein, I see the role of the movement as an essential vehicle for disrupting hegemony, in honoring the unruly and challenging power as a social justice issue.

Terms- Postsecondary Education

In 2008, the Reauthorization of the Higher Education Opportunity Act ushered in a new wave of postsecondary education (PSE) programming for students with ID/DD across the country. This federal mandate set the stage for Institutions of Higher Education (IHE's) to open their doors to students with intellectual disabilities, with relatively broad guidelines that has resulted in a varied spectrum of approaches to PSE. The majority of programs are 2 years in length, with a handful of four year programs nation-wide.

A hierarchy of approved approaches has developed since the beginning of the movement, with "fully inclusive" as the ideal, "hybrid" as the next most acceptable structure, and "segregated" as the least desirable option (Grigal & Hart, 2013). Students attending fully inclusive programs generally audit existing courses, students in hybrid models generally audit and/or take a combination of existing courses and courses designed by the PSE program and students attending segregated programs exclusively take courses designed by the PSE program. General expectations such as the federal guidelines listed in Table 1 are consistent, but individual program specifics vary wildly from IHE to IHE, as noted above.

Table 1. Definitions Found in Title VII, Part D, Section 760 of the Reauthorization of HEOA 2008 (Lee, 2009)

<p>The term “comprehensive transition and postsecondary program for students with intellectual disabilities” means a degree, certificate, or non-degree program that is—</p>	<p>The term “student with an intellectual disability” means a student:</p>
<ul style="list-style-type: none"> • offered by an institution of higher education; • designed to support students with [intellectual disabilities] who are seeking to continue academic, career and technical, and independent living instruction at an IHE in order to prepare for gainful employment; • includes an advising and curriculum structure; and • requires students with intellectual disabilities to participate on not less than a half-time basis, as determined • by the institution, with such participation focusing on academic components. 	<ul style="list-style-type: none"> • with mental retardation or a cognitive impairment, characterized by significant limitations in intellectual • with mental retardation or a cognitive impairment, characterized by significant limitations in intellectual and cognitive functioning; and adaptive behavior as expressed in conceptual, social, and practical adaptive skills; and • who is currently, or was formerly, eligible for a free appropriate public education (FAPE) under the Individuals with Disabilities Education Act.

More background and context regarding the history of education for students with ID in the United States, leading up to the contemporary postsecondary education movement will be provided in Chapter one.

Terms- Models of Disability

Understanding the different models that shape discourse, advocacy and policy such as those that govern postsecondary education, is an essential place to start in the process of developing a more critical eye to disability. The most widely accepted models that have been theorized about in the US are the medical model and social models of disability. The medical approach has historically been the predominant lens through which disability has been framed in the US, with a focus on identification of deficits/sickness/disorders that need to be treated and/or fixed (Kanter, 2014). This approach is anchored in pathology, in the perception that disabled bodies/minds are inherently wrong and in need of righting. In the 1970's disabled scholars and activists began to aggressively challenge this model and demand a reframing of disability as a social construct, an action that essentially sparked the creation of the disability studies tradition (Kanter, 2014)..

The social model of disability places emphasis on society's complicity in creating "physical and attitudinal barriers" that disable people "with various impairments and prevent them from exercising their rights and fully integrating into society" (Kanter, p.10). The impairment is not seen as the problem in this model, and disability is seen as a social construct that arises from imposed societal limits. Scholars, researchers, advocates and activists who have found the medical model to be unacceptable, have most broadly embraced the social model. Kanter (2014) further clarifies that critics find it problematic that the social

model calls for a disconnect between a socially imposed disability identity and the lived experience of having an actual impairment, and that folks with disabilities who are unwilling to deny the reality of how their physical and or intellectual impairments inform their identities, have expressed a need for alternative approaches.

Kanter (2014) speaks to a number of alternative approaches to disability including cultural and human rights models. The cultural model as Kanter describes it, has a “critical and postmodern” focus that stresses the way that “statutory, regulatory, and political processes” impact disability identity, rather than focusing on impairment (p.12). This model is intersectional in that it asserts that disability is one of many identities that are constructed as a result of cultural forces (p.12). The human rights model, which affirms the “basic human rights of all people with disabilities” is unique to other models in its insistence on the right to legal capacity, including folks with intellectual disabilities. This approach demands that people with disabilities be respected and valued as “subjects of their own lives” who hold the same rights as all people (p.13). This model holds particular significance for programs like ours, that focus so heavily on self-determination and advocacy and look for student outcomes in those areas. The models are discussed in more detail in chapter 2, with an eye to how they inform my position and our program’s philosophy.

Terms- Acts of Naming

A few important words here on language and the act of naming oneself. Within the disability studies community, scholars and researchers who claim that identity frequently use the term “disabled” to describe themselves. This a very purposeful reclamation, that is tied to the ways in which disability studies claims affinity with the social model, defining disability “not as an individual defect but as the product of social injustice, one that requires not the cure or elimination of the defective person but significant changes in the social and built environment. (Siebers, 2008, p.3). This is in opposition to the medical model of disability, which as stated before, “defines disability as an individual defect lodged in the person, a defect that must be cured or eliminated if the person is to achieve full capacity as a human being. (Upias, 1972, p.3).

Understanding the danger of the medical approach in recognizing the “unnecessary and violent exclusion” of folks with disabilities from society (Upias, 1972, p.6) is particularly important to those disabled scholars and activists who want to be sure that efforts are directed “not at the cause of our oppression, but instead at one of the symptoms” (p. 4). Language that avoids the tendency to concentrate on the “assessment of the individual” and that seeks “remedy in the opposite direction from the social cause” is a crucial element of advocacy that does not “divert attention from the real problems” of disability (p. 13). For these reasons, the term disabled is preferred by many scholars who resonate with the social model of disability.

In contrast to this mindset that is so predominant within the UK, scholarship and activists within the United States have taken up the mantle of “person-first language,” which “respectfully puts the person before the disability” making the point that “a person with a disability is more like people without disabilities than different” (Snow, 2001, n.p.). This approach is a response to language that dehumanizes and centers the deficit/condition to a person’s identity. Proponents of person first language use “person with” as descriptors, and the disability is presented as an adjective like any other personal characteristic, not as a central identity component.

This is a reflection of the rights-based, US mantra that “people are people,” a philosophical call for acknowledgment that has been a large part of my lens since I first began working in the field. I think that it is important to note, that although American scholars have a history of critiquing the medical model, the emphasis on the phrase “with diagnosis/disability/disorder” is still a reflection of a more medicalized/diagnostic approach to naming identity. I struggle with this within my own critical positionality, but I also respect that person first language has been claimed as the preferred approach by the students with whom I work and research. In an effort to honor both of these important perspectives, I will use the term disabled when discussing scholarship by those who represent the UK tradition, and “person or student with disability” as I reference American scholarship including our own.

Terms- Inclusive Research

Another term that is central to this work, and which I think is important to clarify, is inclusive research. This is a term that has come into popularity as a descriptive way “to shorthand the various strands of research in which people with learning difficulties have been involved as active participants (Walmsley, 2001), including participatory and emancipatory research (Walmsley, 2004). As I believe that many will consider this research to be inclusive, I think that is important to be clear about how I use the term here.

Inclusive research is a term that I claim with some trepidation. The word inclusive is problematic in that it reinforces the binary of included vs excluded, as if there is an optimal, desired state to which individuals want to be included. Walmsley (2004) has argued as much, saying “that we researchers in learning disability are more influenced by a crude interpretation of normalization than we care to admit, an interpretation which attempts to deny difference” (p. 67). This is echoed by Harbour (2013), who highlights that push to “include” individuals from an oppressed group into the “normative” population reinforces the status quo.

Inclusive research promotes the polarization of non-disabled and disabled researchers where the idea of the expert is perpetuated (Walmsley, 2004). As I have come to be influenced by activists and other critical scholars with and without disabilities with similar ideas, I have also begun to “trouble” the term. I recognize however, that the students with whom I work and whose voices are at the center of this research have identified inclusion as an important goal. In

honor of that perspective, I choose to use the same term and connect with that research tradition even, as I question the language. Having provided a background of this foundational term and those before it, I now move on to describe the history and development of this study.

Evolution of a Study

History of Beyond Academics. This study evolved from my professional role as academic director for Integrative Community Studies (ICS), a four-year college certificate for students with Intellectual and Developmental Disabilities (ID/DD) at the University of North Carolina at Greensboro, as well as my consultation to Beyond Academics (BA), the non-profit partner that is central to providing support to this target community of students, and that also served as the incubator for the program of study. BA was initially conceived of by a group of parents and young adults in Winston-Salem, NC who were frustrated by the limited post-high school options for students with ID/DD.

After learning about a college-based program for adults with ID/DD in Maine, this forward-thinking group approached CenterPoint Human Services in Winston with the idea of developing a similar program in NC. The Consumer-Initiated Program Planning Committee, made up of interested adults receiving support, families and community partners began meeting in November of 2004. A local service provider helped move the program from a plan to a reality by providing initial funding, guidance and staffing with which to grow.

BA quickly changed its course from a two-year program to a four-year program in response to clear communication from students that they wished to have four years to experience and grow from college life like their matriculating peers. From its inception, the program has demonstrated a deep commitment to incorporating student voice and desire into its evaluation and program development activities, and BA has had a quality improvement process that involves students, non-profit staff, university staff, faculty and community members.

In 2015 however, it was determined that this process had become less effective and in need of a change in approach, coinciding with my engagement in a community engaged research (CER) course in my PhD program. The leadership team from the non-profit, including myself, decided that the use of CER had the potential to provide more meaningful feedback that was more in line with the philosophy of the program, and that it could better illuminate the efficacy of the program, as determined by the main stakeholders, the students. This research opportunity was also determined to be an important vehicle for adding to the existing body of literature related to postsecondary, higher education programming for students with ID/DD. The research discussed here represents the first stage of what will be an ongoing community engaged process.

Trajectory of Research/My Position

This research approach also evolved from a pilot study that I conducted in 2014 that “grew out of an assignment for a research methods class where, initially, there was a desire to utilize critical, ethnographic research methods to explore the perspectives of college students with intellectual disabilities (ID)” (Harrington & Brown, 2015). I partnered with a student from the program to conceptualize the study, and although the pilot was not IRB approved and therefore reportable, a narrative of the collaborative process itself was co-authored by myself and that same student from the program. The following is our joint positionality statement from that writing,

Our inherent belief that knowledge and awareness are critical tools for “emancipating the oppressed and improving the human condition” (Lincoln, Lynham & Guba, 2011, p.114), informed our research activities, and encouraged us to explore participatory methods where “knowledge is founded in transformation” (Lincoln, Lynham & Guba, 2011, p.114) and where that “transformation is based on democratic participation between researcher and subject” (Lincoln, Lynham & Guba, 2011, p.102). Having experienced our own personal transformation and “searches for truth” through spoken word and advocacy, we were particularly drawn to research techniques that create opportunities for all participants to do the same—to those techniques that “support social transformation and revolution” (Lincoln, Lynham & Guba, 2011, p.106). This belief in the impact of social structures like “freedom and oppression, power and control” also drove our research efforts towards the production of knowledge that can “change existing oppressive structures and remove oppression through empowerment” (Lincoln, Lynham & Guba, 2011, p.103).

We believe that we are our own experts in our life experiences, and that we must not give someone else power over our “story.” This perspective is a prime example of why Kathy Hytten says that “the alliance between critical theory and qualitative research is problematic and uneasy” (Hytten, 2004, p.95). How do we, as researchers, ensure that we are not claiming

authority over the “stories” of our research participants and partners? How do we structure research so that it helps to “illuminate how theory informs lived experience” and respects the narratives/voices of those being researched (Hyttén, 2004, p. 95)? These were critical questions that we wanted to explore through this collaboration.

I include the statement in its entirety because it is a reflection of essential ideas that push me as a researcher, professional and engaged community member. These ideas, as well as the experiences that I have had with co-production of knowledge and my own poetic sensibility greatly impact my own approach to scholarship. In the same vein, I also offer the following poem as a way to highlight this in a more embodied way:

critical
emancipatory
community engaged
research
resonates within me
finding value in the articulation
of that which has previously been
unheard
undervalued
pushed to the margins
product of black, southern family
I know suffocation
family system expectations
of blind obedience

and quiet suffering
woman born
to black mother and white father
I know the feeling
of voice not being counted
because it is not
authentic
or credible enough
to the very community to which you most wish
to belong
mother of black boy growing to man
I know the watching of educators
who try to silence
with labels
child who questions everything
and moves through learning
on all counts
my mother was the catalyst
that helped me find my way
past limitations
her books
her ideas
and her unrelenting expectation
that I question everything
made life

uncomfortable
but out of that discomfort
grew a critical viewpoint
that became my anchor
even when I didn't have the language
to define it
as critical
even in finding my own personhood
beyond her influence
I could still hear her voice in my ear
see her thoughts on the pages of the books I read
even as I discovered myself
in spoken word revelations
she continued to pop up
in my writings
creeping into my metaphors
leaving her mark
like kilroy
my experiences
have molded my view of the world
my belief that the desire for power is at the foundation
of this country's cultural, political and social scaffolding
creating inequities
and pockets of oppression across lines
of race, ethnicity, gender, ability

and so many other
ways to be different
my understanding of truth as it exists
and my relationship to knowledge
will all continue to influence me
guide me with gentle
and not so gentle insistence
as I find my place
within the workings of research
and scholarship

At the Intersection- Map of a Dissertation

I believe that the best way to illustrate this study is by using a Venn diagram to show how it is situated at the intersection between research, praxis and theory (see Figure 3). The perspectives of students with ID in higher education are being centered (CER) which requires an understanding of educational practice/pedagogy and student agency (Praxis), as informed by critical frameworks like disability studies (theory). Within each “circle” there are a number of concepts that inform this study. I will introduce them briefly here, and then will explore them each more deeply in the following chapters.

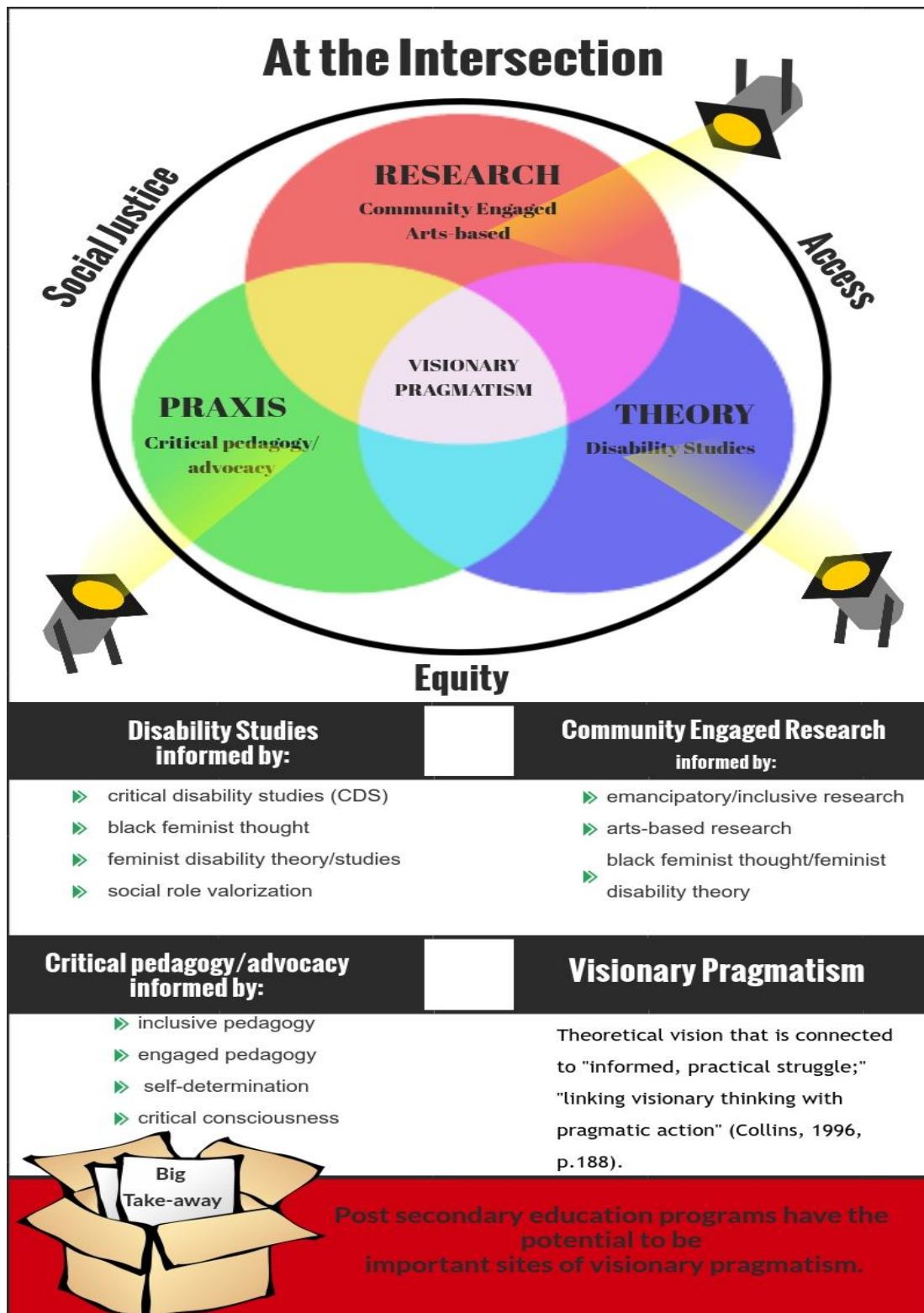


Figure 3. Visual Overview of CER Study.

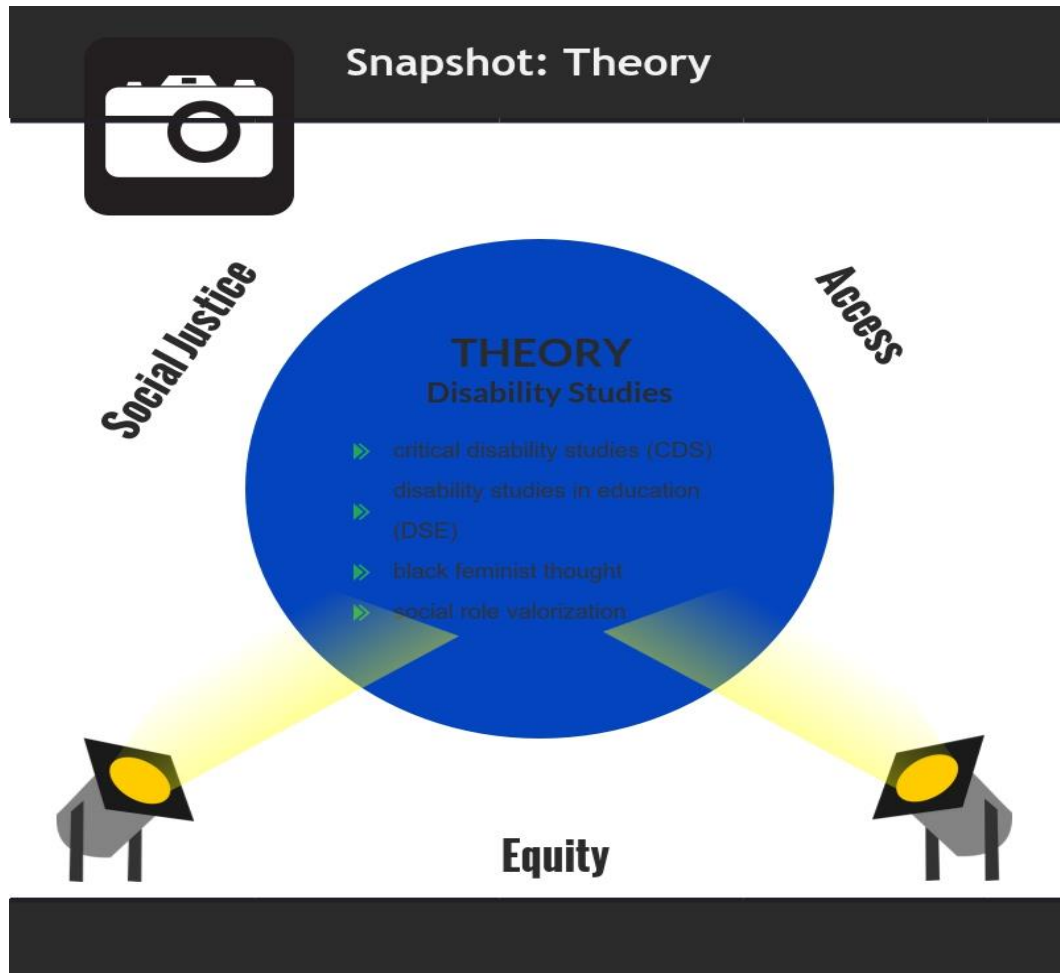


Figure 4. Theoretical Component of Study Overview.

Snapshot- Theory

Chapter 1 ties theory to postsecondary education as a movement and as a research platform. With its focus on equity, social justice, emancipatory research and challenges to the medical model of disability, this study situates itself firmly within the Disability Studies (DS) tradition. Disability studies represents an interdisciplinary body of scholarship that centers disability identity and perspective in its discourse, with the goal of balancing power inequities

experienced by people with disabilities in society. As Kanter outlined earlier, essential ways that DS differs from traditional approaches to disability, include a shift away from medical/diagnosis/treatment explanations of disability, to more cultural, social, political explanations, an emphasis on ability and dignity vs. tragedy and deficit, a positioning of the person with the disability as expert, and the inclusion of fields that have not traditionally framed disability as social construct (Kanter, 2014).

Although there is disagreement about how these models may or may not respond to the “real, lived experiences” of folks with disabilities and/or that “naming the different models is less important than the critical viewpoint they espouse,” I would argue that Kanter’s (2014) compelling stratification of disability models offers a number of engagement points for our program and others like it. When elements from each of the models are collectively considered and presented, as I believe they are in our program, the result is a more critical take on disability studies. For the purposes of this research, I will refer to a critical disability model in this sense; as an amalgamation of elements from the disability models that Kanter references (see table 1). These elements are by no means exhaustive in their “defining” of a critical viewpoint, but I do think that there is value in having this framework as a theoretical jumping off point.

Although DS does include a wide variety of disciplines that engage disability critically, this research focuses specifically on Disability Studies in

Education (DSE). DSE is committed to the same goal of equity, seeking to bring disabled perspectives forward, specifically situated within educational research.

Table 2. Critical Disability Model

Elements of Critical Disability Model (based on Kanter, 2014)
<ul style="list-style-type: none">•disability acknowledged as part of human experience (social model)•society "disables", not impairment (social model)•impairment does not define person's value and abilities (social model)•statutory, regulatory, political processes "disable" (cultural model)disability occurs alongside other identities (cultural model)•disability should be examined through cultural lens (cultural model)•people with disabilities have the same rights as everyone else (human rights model)•disability diagnosis cannot be used as determinant of legal capacity (human rights model)•people with disabilities are "subjects of their own lives" (human rights model)

It embraces critical pedagogical practices that challenge ableist systems and “normative educational contexts” that are often “designed by and for able-bodied persons”(Goodley, 2007, p. 318), and as such, like the critical disability model, I consider it to be part of a larger umbrella of Critical Disability Studies (CDS). Critical disability theory/studies that values the “variety of traditions within critical pedagogy” that share the “broad objective” to, as McLaren (2003) has said, “empower the powerless and transform existing social inequalities and injustices (Hyttén & Bettez, 2012, p. 17) is a key tradition needed to enrich and balance the current field of PSE research. In their study, Cory et al. (2010) provide a great example of this tradition in their case study of student activism, which was used

to examine how disability studies theory can effectively be used to change disability services on campus. Few educators within higher education situate their research in this area (Rocco & Delgado, 2011), and as PSE programs move to become more deeply and seamlessly integrated within higher education communities, this type of research is even more crucial.

In contrast to critical disability studies, self-determination and theories related to the concept are a significant component of current PSE research, although they are not always successfully used to anchor discussion of research activities. Michael Wehmeyer has been perhaps most prolific and effective in defining self-determination theory and examining its position within educational practice (Wehmeyer, Abery, Milthaug, & Stancliffe, 2003; Wehmeyer, Agran & Hughes, 1998; Wehmeyer, Agran, Palmer, Milthaug, Martin & Wehmeyer, 2003; Wehmeyer & Kelchner 1995). As cited by Lachapelle, Wehmeyer, Haelewyck, Courbois, Keith, Schalock, Verdugo & Walsh (2005), Wehmeyer defines self-determination as “acting as the primary causal agent in one’s life and making choices and decision regarding one’s quality of life free from undue external influence or interference” (p. 741).

There is often great discussion about the importance of self-determination for students with ID, but as Deborah Jameson (2007) has pointed out, very few postsecondary studies have effectively examined the impact of self-determination on the success of students with disabilities, and that those that do “remain unclear about the reasons for successful outcomes” (Jameson, p. 27). I agree

with her analysis, and have experienced this anecdotally through my participation on local and state PSE committees and alliances- there is a great need for outcome research, and as my theoretical position would suggest, I believe that a significant portion of that work needs to be anchored in theory that keeps equity and social justice at the center.

Engagement in research that maintains such a social justice focus, is an essential part of my theoretical lens as the lead researcher. Beyond the theories mentioned already, as an academic, educator, researcher and artist, I have also been heavily influenced by the thinking of black feminist/womanist scholars, by feminist disability studies, as well as the call for inclusive/engaged pedagogy. Overlapping elements within these traditions that center lived experience, interdependence, reflexivity, voices of folks at the margins, agency, resistance, the collective, valuing different ways of knowing, access, and mutual engagement between student and teacher are foundational to my way of understanding the world (Dadds, 2011; hooks, 1999; Carter, 2015). I believe that exploring the intersection between these traditions can significantly inform CDS scholarship. Chapters 1 and 2 provide definitions and a more complete overview of these intersections, as well as how they impact the next element of this research.

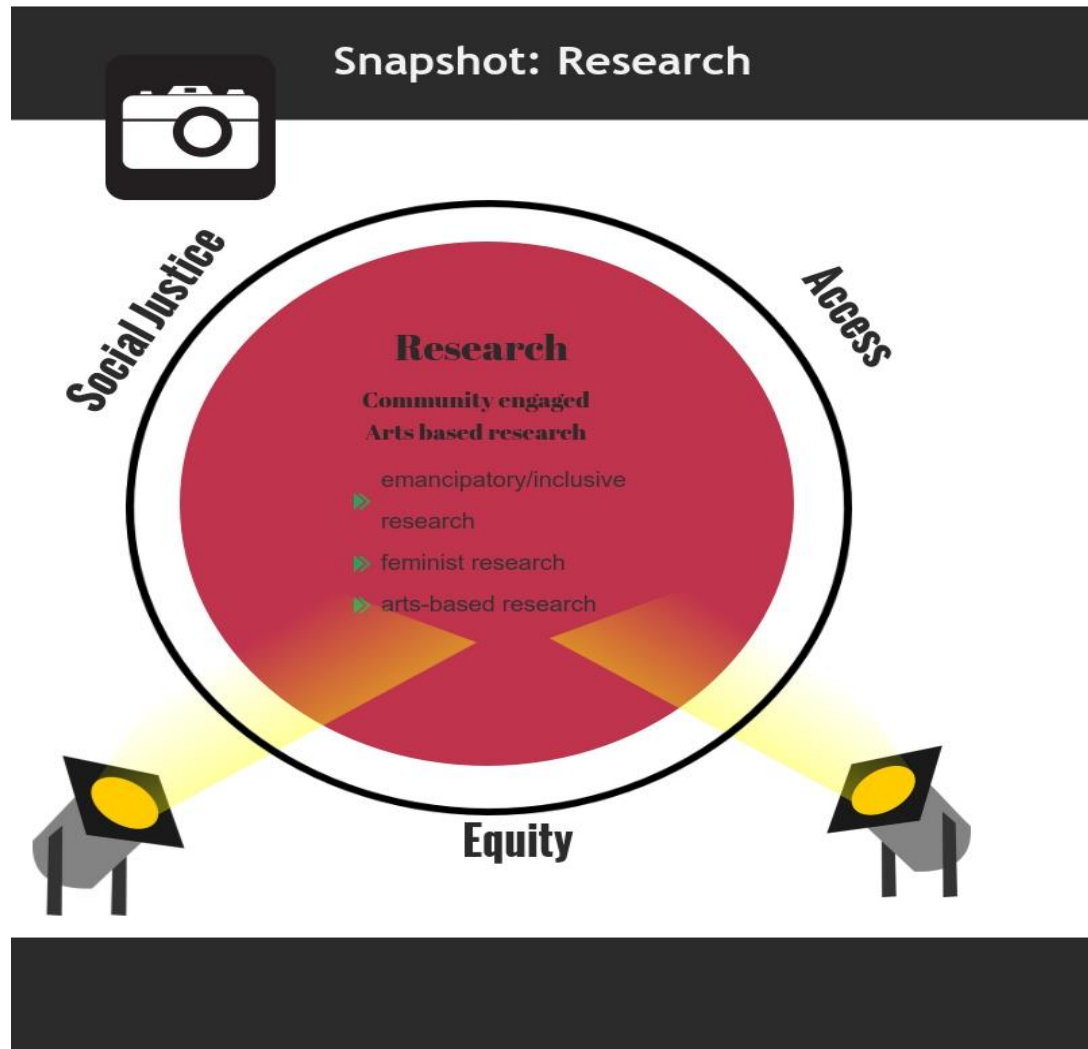


Figure 5. Research Component of Study Overview.

Snapshot- Research

I refer to the methodological approach in this study as community engaged research (CER). Within the DSE tradition, this type of research is generally considered to be “emancipatory” in nature, and has been used both in a broad sense to mean a number of methods that assume that people with disabilities are the experts on their lives and the experience of living with a

disability, as well as a more specific method of “critical social research” that has roots within the feminist tradition and focuses on the facilitation of “a politics of the possible by confronting social oppression at whatever level it occurs” (Oliver, 1992 as cited by Watson, p. 95). I find the term emancipatory to be problematic when framed in the passive sense, as in someone who needs to be emancipated “from” something. When I use it here, I am referring to methodological approaches that trouble that passivity and put stakeholder voices and their agency “to” at the center of the research agenda.

Like emancipatory research within the feminist tradition, I argue that community engaged work is a way to combat the divide between “disabled and non-disabled people, the researched and the researcher” (Watson, p. 95). Community engaged research is an approach that can be described as a marriage between the two goals of “community development” and “knowledge generation to achieve social justice ends” (Flicker et al., 2007, p. 240), and it is an impactful way to be sure that the voices of the students in our program are being centered in a way that leads to action and agency and social change. It is a methodology that involves “collaboration between trained researchers and community members in the design and implementation of research projects aimed at meeting community-identified needs” (Strand, 2000, p. 85). Stakeholders are ideally involved in every step of the process, “from identifying the research question to formulating action proposals that derive from the

research results” (Strand, 2000, p. 85). bell hooks (1990) encapsulates the caution that I think is so essential here when she says:

No need to hear your voice when I can talk about you better than you can speak about yourself. No need to hear your voice. Only tell me about your pain. I want to know your story. And then I will tell it back to you in a new way. Tell it back to you in such a way that it has become mine, my own. Re-writing you, I rewrite myself anew. I am still author, authority. I am still the colonizer, the speaking subject, and you are now the centre of my talk’ (Hooks, 1990, p.151-152).

Critical processes that highlight stakeholder voice and avoid this type of coopting point to community engaged research as an ideal vehicle for programs that are committed to the spirit of emancipatory work.

CER challenges ideas of neutrality and objectivity in research, the generation of knowledge that is of genuine interest to all co-researchers, collective processes of “inquiry that expose ideological, political, and social processes underlying and permeating systems of inequality” (Lykes & Coquillon, 2006, p. 298). A primary goal of postsecondary education (PSE) programs serving individuals with ID/DD is to empower students in the academic process, as well as to provide a breeding ground for self-advocacy and self-determination. As these students are learning these skills through their academic programs, empowering them to be fully contributing members of the research team that seeks to understand their experience in the program only makes philosophical and practical sense. This is what makes postsecondary programs like my own such valuable sites for participatory research efforts.

Erevelles (2009) asserts that one of the barriers with these types of qualitative research methodologies with people with multiple or significant disabilities, is the difficulty in understanding the social world of someone whose “experience of concepts and communications is so uncertain for us” (Kathleen Weiler, 1988 cited by Erevelles, 2009 p. 70). The response of critical education theorists regarding the configuration of “human agency”, according to Erevelles, is that in “the face of real physiological differences” disability is avoided or “arbitrarily added” to other sociological categories like race, gender and class (p. 70). It is this point that I think makes CER such a strong methodology for students with ID/DD; co-researchers are able to draw on multiple relationships and modes of communication from within the community of co-researchers to help unearth those perspectives and experiences that Erevelles has described as so uncertain.

I think that capturing and valuing multi-modal forms of expression helps to address Erevelles’ concern about uncertainty. Chapter 2 provides a backdrop of research methodologies in the US to which Erevelles references, against which community engaged research and arts based inquiry are framed. Arts-based research is, as Valle (2015) describes, research that “relies upon one or more artistic process that may be used in generating, analyzing, and/or presenting data that emerges from collaboration with the people we engage in inquiry” (p. 67).

Valle (2015) cites scholars like Elliot Eisner and Sara Lawrence-Light who are “widely recognized” for the ways in which they have integrated qualitative research and narrative fiction and argues that ABR has earned a scholarly reputation for “broadening and deepening qualitative research” in the 40 years since its beginnings (p. 68). “The points of compatibility between ABR and DSE,” says Valle, “are evident in a shared commitment to challenge a world; that is to bring marginalized voices to the forefront, raise critical awareness, and contribute to social change” (p. 69). I resonate deeply with this as well as the idea that artistic expression is a valuable way for people to show what they know about the world, to express their lived experience.

As a poet, I also gravitate towards poetic inquiry as a way to “expand the repertoire of techniques used in data representation, analysis, and interpretation as we capture the lived experience of our participants” (Janesick, 2016, p.59). Adrienne Rich echoes this when she says that the use of metaphor and poetic language allows people to challenge “apparently self-evident propositions” about society and how it operates, “not through ideology, [but] by its very presence and ways of being, its embodiment of states of longing and desire (Rich, cited by Scheurer, 2011, p.159). Poetry allows us to “illumine the surface of things with imagination’s beam” (Critchley, p.179-180) through the unique perspectives that are embodied by those who are engaged in research at all points (Duarte, 2010).

For the students with whom I work, who have varied communication styles and abilities, I also think that poetry is an effective way to “hear” the uniqueness

of individual voices by virtue of capturing the “essences of what’s said, the emotions expressed, and the rhythm of speaking (Glesne, 2011, p. 250). Chapter 2 sets the stage for the ways in which poetic inquiry can be used as an alternative to more traditional approaches to analysis, and Chapter 4 describes the way that it was used in this research.

Chapter three uses a visual approach to provide an overview of the theoretical background and research methodologies, including critical disability studies, the intersection with black feminist thought, feminist research, pedagogy and visionary pragmatism, and will provide a timeline of the history of special education, inclusion and postsecondary education in the US. Disabled scholars Docherty et al. (2006) make an important point when they state that scholarship in disability studies is written “so that professionals can look at it” (p. 434). They argue that such scholarship is not “accessible to learning disabled people” is full of “jargon” that “keeps us out,” and they make a call for information that uses visuals and large print so that it is more accessible (p. 434).

If this work is to be a reflection of community engaged research that engages disabled scholars, then it is paramount that it is also accessible to the folks that are at its center. “The more channels students (and writers generally) have to select from when composing and exchanging meaning,” Walters (2010) cites, “the more resources they have at their disposal for being successful communicators (Selfe & Takayoshi, 2007 cited by Walters, p. 437). For this reason, chapter 3 has been formatted as part graphic novel/ part infographic, for

wider accessibility and in large part because the “inherent multimodal nature of this form, which combines text and image and asks readers to interpret or “read” other non-linguistic elements such as frames and “camera” angles,” allows for a different engagement with the material- is representative of a different “way of knowing” (Hughes & Morrison, 2014, p. 117).

Graphic novels/formats “promote multiple modes of expression or ‘dual pathways’ that provide more than one entry point to information”, and my dissertation is an opportunity for me, again, as an educator, to reflect universally designed pedagogical practices (Hughes & Morrison, 2014, p. 118). As such, this chapter is an important example of praxis, which is significant, because unlike the ways in which many other examples of PSE scholarship are presented or reported, the nature of this study makes it difficult to isolate theory and practice.

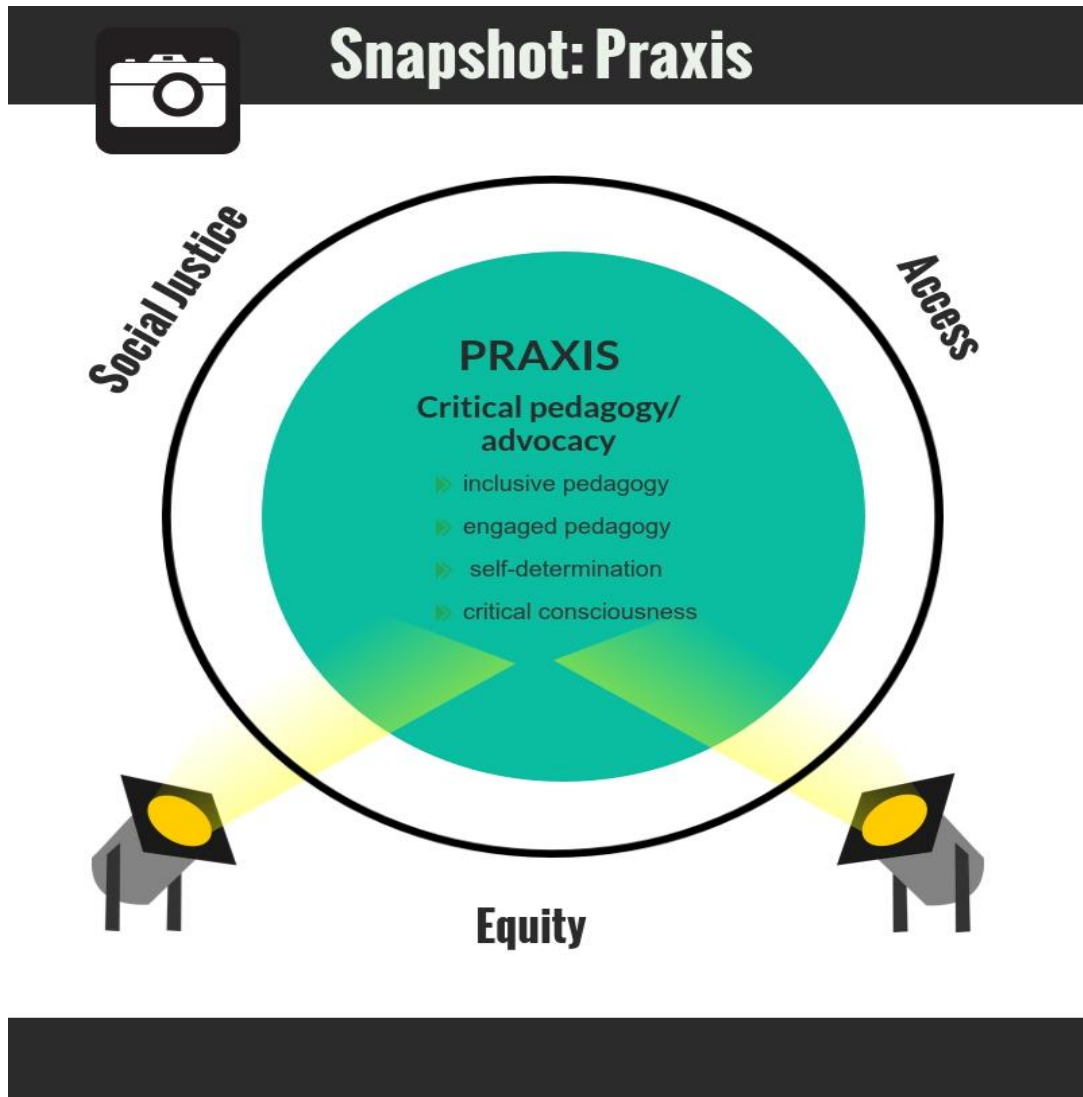


Figure 6. Praxis Component of Study Overview.

Snapshot-Praxis

Praxis, the enactment of theory is an important element, particularly as it relates to pedagogy and advocacy. In relation to this research, I have found it helpful to think about and discuss praxis in three areas: as practice for the educator, practice for the person and practice for the community. All of these

practices together represent what I refer to as “critical advocacy,” strategies that explore individual and collective responsibilities to challenge discrimination and inequity and are required for students to have more access, value and engagement within the hallowed halls of higher education.

Critical practice for educators cannot be divorced from critical theoretical foundations that reject any teaching practice that “does not directly address the needs of victims of oppression” (Kincheloe, 2008, p. 49). Feminist Disability Pedagogy cannot be divorced from the feminist theories that are at its foundation. Discussion about implications of this work on pedagogical practices in higher education can be tied to black feminist thought around the engagement of multiple experiences, perspectives, bodies and minds in the classroom. Results from this research presented in Chapters 5 and 6 speak to a need for a better understanding of the intersection of universal design, inclusive pedagogy and engaged pedagogy. If students with ID are to achieve the level of academic access that they are telling us that they desire, then this has significant implications on work that needs to be done in higher education; a transformation of pedagogy that is indeed a practice for educators.

Practice for the person is the second area of praxis that has come forth in this research. Student agency and critical practices of self-determination are impossible to untangle from theories of self-determination and emancipation. Therefore, I have situated self-determination both in the theory component as well as here in the praxis component. The enactment of self-determination is very

much at the center of PSE programming like ours. Kincheloe (2007) speaks to the importance of exploring this site of praxis within education here,

Since ideological education takes place in a variety of domains, study is demanded of not only the social (macro-) and individual (micro-) level but the institutional (meso-) on as well. In this integrative approach, the interactions of these three levels in the process of ideological education, the ways they operate in the construction of the social and individual, are significant... For example, I am concerned with not only the social construction of the individual's knowledge but also with the individual's responsibility for his or her actions. This attention to individual volition is often missing from some articulations of critical education. (Kincheloe, 2007, p. 27)

This study provides an opportunity to look at how Kincheloe's idea of individual volition, or practice for the person, can be explored in relationship to theory. This engagement of individual action and theory can also be framed as what Patricia Hill Collins (1996) calls visionary pragmatism, the "creative tension (that) links visionary thinking and pragmatic action. (p. 188). Visionary thinking according to Collins, "can be conjured up in the theoretical imagination, yet pragmatic actions require being responsive to the injustices of everyday life. (p. 228). This is an important theme that became very clear in the data. Students see college as a site for learning about and practicing self-determination, so that they can become, as Kanter (2014) says, the "subjects of their own lives."

Practice for the community encompasses transformation of educational systems that devalue unruly bodies and minds. An important element of that process highlighted in student data, is the need for a contemporary take on social role valorization, where research is used to help expand the way that society at-

large values folks with disabilities. This research is significant in that it is an example of how this can be executed, an implication for future research which is discussed in in the conclusion.

In the conclusion, I address this significance as part of a larger discussion about the ways that this research can inform/impact local and national PSE programming, expanding non-traditional research methods, and access to higher education. I tie the results of data analysis presented in chapters 5 and 6 to calls for more engaged pedagogy, higher education system transformation, provision of more opportunities for disabled scholarship and socially just treatment for students with ID on college campuses.

CHAPTER II

PSE LITERATURE AND THEORETICAL FRAMEWORK

Since the Reauthorization of Higher Education Opportunity Act of 2008 we have heard more and more voices of students like Greg and Danial, reflecting a new movement in higher education: students with intellectual and developmental disabilities (ID/DD) who are attending college. Greg's words are a reflection of the ways in which college has been broadly characterized in this country, as a time for unlocking opportunities, increasing independence, self-exploration, and having new life experiences (College board, 2016). It has not however, traditionally been an option for students with ID/DD, with the exception of a limited few that were able to gain access to the small number of postsecondary education programs that have been in existence since the 1970's (Neubert, Moon, Grigal & Redd, 2001).

So it is exciting that over these past ten years, high school graduates with ID/DD in larger numbers have begun to demand access to opportunities for the personal and professional growth that the College Board promises. It is also exciting that this movement towards inclusive higher education requires a reevaluation of some of the elitist philosophies and exclusive educational practices that have played a part in restricting postsecondary choice for students

with ID/DD. As noted by Grigal and Hart (2010) in their comprehensive text on the postsecondary education movement, the push is not a new one as there “has been evidence of this emerging practice in the literature for over 30 years (Baxter, 1972; Bilovsky & Matson, 1974; Caparosa, 1985; Corcoran, 1979; Dahms, Ackler, & Aandahl, 1977; Daily, 1982; Doyle, 1997; Duran, 1986; Frank & Uditsky, 1988; Goldstein, 1993; Hall, Kleinert, & Kearns, 2000; Jones, & Moe, 1980; McAfee, & Sheeler, 1987).

The Era of Postsecondary Education

Early iterations of postsecondary programs were generally focused on deinstitutionalization, community integration and striving for normalization, provided in segregated settings (Neubert, Moon, Grigal, and Redd, 2001). By the 1980’s, as the focus of special education shifted to transition and employment, so did PSE programs began aligning themselves with Section 504 of the Rehabilitation Act of 1973 (Grigal & Hart, 2010). As Grigal and Hart (2010) note, this shift sparked a change in perspective, reflected by an emphasis on student identity in the literature in the 1990’s. The literature from these eras, is not as extensive as we would like, and even with the recent explosion of PSE programs, they highlight the following,

The current base of knowledge about PSE services for students with dis. Is most often focused on students with learning disabilities, including physical or sensory impairments, who comprise the largest percentage of college students with disabilities (NLTS-2, 2006). Much less is known about the various types of of PSE programs, and associated activities and outcomes, for students with ID, as these students have not typically been

supported in their efforts to seek out college. In addition, many recent national education studies provide little if any information on students with ID. This is unfortunate, as such an effort would allow for meaningful comparisons between disability groups. (p.10)

Current research efforts, as compiled by Grigal and Hart (2010), provide “descriptions of the characteristics, activities, and or outcomes of students” at state and national levels, yet “the limited information currently available does not reflect the vast variation in the array of services provided” (p.11). I am in agreement in fact, that employment readiness has by-and-large been the most enduring theme in PSE literature to date (Migliore, Butterworth & Hart, 2009; Grigal & Sulweski, 2012; Grigal & Hart, 2010), while there has been a dearth of writing on how programs are evaluating the holistic growth that can occur during the college years (Gurin, Dey, Hurtado & Gurin, 2002). Other buzzwords that are taking center stage in the PSE discourse are disability-identified terms and/or outcomes like transition, independent living, advocacy, productive citizenship, self-sufficiency, inclusion, and equal access. The field is still dominated by professionals, disability advocates and scholars, and with the exception of a few researchers like Maria Paiewonsky at UMass, there are relatively few examples in the US where student voice is centered in scholarship, research *and* reporting of program outcomes.

Meg Grigal, Debra Hart, and Cate Weir, scholars that have played an instrumental role in the development of the Postsecondary Education (PSE) National Coordinating and Technical Assistance Center (NCATC) based at the

University of Massachusetts, have provided some of the most comprehensive and prolific surveys about program development in the field. In each study, these authors take advantage of the opportunity to introduce postsecondary education as a social justice/access issue (Grigal, Hart & Weir, 2012; Hart, Grigal & Weir, 2010; Neubert, Moon, Grigal & Redd, 2001), often referencing resources like David Leonhardt's (2011) NY Times article, *Even for cashiers, college pays off*, in which Leonhardt tells us that

The evidence is overwhelming that college is a better investment for most graduates than in the past. A new study even shows that a bachelor's degree pays off for jobs that don't require one: secretaries, plumbers and cashiers. And, beyond money, education seems to make people happier and healthier...the general skills that colleges teach, like discipline and persistence, may be more important than academics anyway, (Leonhardt, 2011, n.p.)

Leonhardt speaks to the idea that students with ID find themselves wanting the same types of post-college outcomes as their college-aged peers.

In their 2012 survey of PSE programs in the US, Grigal, Hart & Weir outline the current state of legislation and policy on postsecondary education, national and state vocational rehabilitation policies and practices, as well as current postsecondary education practices for students with ID. In an effort to provide some standardization to the field, they also offer 8 areas of consideration for program development, including academic access, career development, self-determination, campus membership, alignment with college systems and practices, coordination and collaboration, sustainability and evaluation (Grigal,

Hart & Weir, 2012). The authors also identify what they see as current research trends in postsecondary education: secondary analysis of datasets, national surveys, stakeholder surveys, model demonstration program evaluation and topic-specific qualitative research (Grigal, Hart & Weir, 2012).

Research highlighting efforts in the field is really in its infancy stage, with much of it focusing on curriculum development, program development, evaluation and teaching practices, etc. (Trela & Jimenez, 2012; Mock & love 2012; Folk, Yamamoto & Stodden , 2012; Papay and Griffin, 2013; Papay and Bambara, 2011; Hafner, Moffat, & Kisa, 2011). Recommended future research on inclusive higher education continues to focus on “practical” gaps in knowledge, such as the impact of PSE programs on outcomes, capturing and monitoring student outcomes, and the impact on K-12 and Transition practices (Grigal, Hart & Weir, 2012).

I believe that the practical role that these authors play in providing technical assistance and support to PSE programs across the country through the NCATC, logically lends itself to a more “program evaluation/development” approach to PSE research, although they themselves have noted a need for “stakeholder” voice and involvement through more varied qualitative studies, and also identify PSE as a social justice issue. In this way, they are connected to those scholars that center the call for more democratic, equity and access based educational practices in their research efforts; efforts that represent another

significant portion of PSE research that is currently available, as I will outline in the next section.

Access and equity are themes common to the bulk of current PSE literature reflecting what Hytten and Bettez (2012) describe as “broad criteria, principles, and constructs for thinking about justice ”(p. 11). Pliner and Johnson’s (2004) study on universally designed instruction provides a powerful look at the moral imperative for access to inclusive education and teaching. They state,

Although institutes of higher education serve an increasingly diverse student body, they have traditionally been resistant to change, especially in accommodating the needs of students marked as “minorities” because of race, class, ethnicity, gender, disability, religion, nationality, or sexual identification or orientation (p. 105).

Pliner and Johnson (2004) assert that systems of higher education must be “totally reconfigured” in order to successfully create inclusive learning communities for each student, and that educational institutions must meet the same challenges that our society as a whole must meet for “full integration and nothing less”(p. 105). Although legislation and social activism have opened the door for students from diverse backgrounds, higher education continues to “perpetuate ways of being and knowing that disproportionately support and reward... white, able-bodied, heterosexual, Christian males” (Pliner & Johnson, 2004, p. 106).

The authors connect the different theoretical frameworks of universal design for learning, multicultural education and social justice education to the

common philosophical goal of meeting the needs of students who have “historically been underrepresented, disempowered, and oppressed within educational institutions” (Pliner & Johnson, 2004, p. 108). This article is persuasive in its arguments for the need to level the playing field and transform our thinking from “placing reactive responsibility on the ‘other’ to adapt to exclusionary structures” to a “proactive process” where all educational practices, from curriculum development to student development programs include the learning needs of all students (p. 109). This type of learning environment will be of particular importance to the success of students with different learning styles, including students with ID.

Thomas Philip (2012) echoes Pliner and Johnson’s call for inclusive educational practices, as he ties the “devastating effects of deficit-thinking, where teachers, schools and society attribute the lack of student achievement to the values, behaviors, and choices of oppressed groups,” to education as a matter of Civil Rights (Philip, 2012, p. 31). He believes that social educators today must view education through the lens of Civil Rights in order to connect truly inclusive education to practices that challenge segregated learning spaces and unequal distribution of resources (Philip, 2012).

...when we say that nothing outside of the classroom matters for a student’s success, we are in effect standing by and witnessing the defunding of communities’ health, nutrition, housing, employment, transportation, etc. We play into the myth that our students’ current and future life situations and opportunities will be significantly different even if

we do not work to transform this society's inequitable distribution of income, wealth, resources and opportunities (Phili. 2012, p. 35).

Philip provides a convincing argument about the importance of challenging deficit-thinking and its impact across all learners. By issuing the same challenge, PSE for students with ID has an opportunity to improve educational practices for all, and to act as a catalyst for the democratic transformation of which Philip speaks.

Bozalek and Carolissen (2012) give us another example of research that is "democratically grounded" as Hytten and Bettez (2012) would say, in its exploration of the impact of socially just education on citizenship and civic engagement. The authors state that the process of moving "ideas and practices residing at the margins of debates" to the center "of discourse" can impact the ways in which "critical citizens may be developed in and through higher education" (p. 9). The article's emphasis on how "normative frameworks" empower hegemonic discourses by "conferring power on certain speaking positions and vocabularies" is a direct reflection of the philosophical/conceptual approach articulated by Ashby and Slee, but then it also goes on to identify and utilize critical feminist theory as a preferred theoretical approach for addressing oppressive practices (Bozalek & Carolissen, 2012, p. 9). By doing so, this study represents what I consider to be a lesser utilized approach in PSE research, one that significantly integrates theory into the core of the research practice. This is an approach that resonates with me as a researcher, and has significantly

informed my own position on the importance/relevance of critical theory and pedagogy in the field of PSE.

PSE as Sites of Self-determination

Researchers have “long advocated the importance of students with disabilities developing self-advocacy and self-determination skills” (Garrison-Wade, 2012, p. 113), and self-determination and theories related to the concept are a significant component of current PSE research—although not always successfully connected by researchers to parallel elements in critical disability theory. As PSE programs move to become more deeply and seamlessly integrated within higher education communities, this type of research will become even more crucial in highlighting ideas like Rocco & Delgado’s (2011) argument that “people with disabilities have unique voices and experiences, the right to self-determination, the right to escape the ‘commodification’ of the labor and disability business” (p. 7-8).

Michael Wehmeyer has been perhaps most prolific and effective in defining self-determination theory and examining its position within educational practice (Palmer, Wehmeyer, Gipson, Agran, 2004; Wehmeyer & Palmer, 2003; Wehmeyer, Palmer, Agran, Milthaug, Martin 2000; Wehmeyer & Kelchner 1995, Wehmeyer, Palmer, Williams-Deihm, Shogren, Davies & Stock, S. (2011). As cited by Lachapelle, Wehmeyer, Haelewyck, Courbois, Keith, Schalock, Verdugo & Walsh (2005), Wehmeyer defines self-determination as “acting as the primary causal agent in one’s life and making choices and decisions regarding one’s

quality of life free from undue external influence or interference” (p. 741). In this same study, Wehmeyer and his colleagues found that self-determination contributes to “enhanced quality of life” (LaChapelle et al., 2005). Authors of a number of qualitative studies have also come to the conclusion that college students with disabilities “attribute their success in postsecondary environments to learning and practicing self-determined behavior” (Morningstar, M.E., Frey, B.B., Noonan, P.M., Ng, J., Clavenna-Deane, B., Graves, P., Kellems, R., McCall, Z., Pearson, M., Wade, D.B. & Williams-Diems, K., 2010, p. 87).

Self-determination has also been defined by Ankeny & Lehmann (2011) as a set of characteristics that allow people to exert control over their lives by “knowing themselves” well enough to be able to identify realistic goals that reflect their personal strengths and weaknesses. In their qualitative study examining the life stories of students with ID at a community college, they identified four “areas of practice” that impact the likelihood that students with ID will develop self-determination skills: the promotion of self-knowledge, advancement of self-determination skills learned before college, increased opportunities to take risks, and opportunities for self-reflective practice (p. 286). This study is one of the few of which I am aware, that identifies “ability to take risk” as a predictor of self-determination. This is a key factor in my opinion, that receives limited attention—to achieve a genuinely self-determined life, students need a “real-life environment to develop and practice the skills and the self-advocacy required to truly succeed in the world beyond school” (Ankeny & Lehmann, 2011, p. 282).

Different PSE Lenses

In her dissertation on postsecondary outcomes for students with intellectual disabilities, Lindsey Farnham (2011) used equal opportunity theory to help frame the inequities that are often present when students with intellectual disabilities desire access to opportunities to “be viewed as a valued member” of their community (p. 55). Farnham heavily referenced Wehmeyer’s contemporary, Dennis Milthaug in her work, who describes equal opportunity theory thusly,

The theory claims that the discrepancy between the right and the experience of self-determination is due to the lack of capacity and lack of opportunity among individuals whose personal, social, and economic circumstances are beyond their control. By claiming that every member of society deserves an optimal chance of securing the good in life, the theory explains our collective responsibility for assuring fair prospects for all. The theory shows that when prospects for self-determination are distributed fairly, they are equally optimal for all (Milthaug, 1996, p. 4-5).

Milthaug (1996) also discusses a model of “empowerment evaluation” which he describes as a process at societal and cultural levels that determines the “extent to which all members of society have a fair chance of pursuing those self-defined ends in life that are most fulfilling.” Farnham ultimately found in her survey of students with intellectual disabilities enrolled in a college, school-to-work program, that training in self-determination was one of the more robust indicators of positive post-college outcomes.

I find studies like this to be a hopeful harbinger of what we are likely to see in future research, but I also find myself critically considering the perspective of researchers like Baker, Horner, Sappington and Ard (2000) who caution the field regarding the development of measures of self-determination, that “without sensitive, valid, reliable measures, self-determination can easily become a concept that is often referenced but devoid of meaning” (p. 154). Although I find myself responding, perhaps somewhat predictably, to their use of “positivistic” language about valid and reliable measures, I do think that there is some merit to their concern about the trustworthiness and meaningful production of knowledge.

It is for this reason that I think that research like Emily Furgang’s (2012) doctoral study anchored in occupational science theory is important- it provides a unique perspective to the field of PSE research. Furgang chose to use the transactional perspective to “holistically” frame her study, in examining how students developed their identities over the course of one year in college. She described the transactional perspective as an approach where “people are understood as relating with their environment rather than as separate entities acting inside of their environments” (Furgang, 2012, p. 4). She was particularly interested in how college acts as a time to “develop student and peer identities while kindling development of future worker and community participant identities” for all students (Furgang, 2012, p. 18). She used student interviews and direct observation to examine identity development for students with ID in college so that the reader could “appreciate the various transactions of personal, social,

cultural, and historical factors that shaped the participant's occupational situations" (p. 4), and hopefully come to see how the exclusivity and elitist beliefs of higher education create an attitudinal and institutional bias against students with intellectual disabilities.

Unlike some of the other doctoral studies mentioned here, Furgang's did a thorough job of examining the position of the author in relation to her study, which is a hallmark of effective critical qualitative research, and which highlights what I see as a gap in the self-reflective approach in PSE research. This gap is part of what draws me to critical and post-critical research methodologies, where self-reflection and transparency regarding one's position as researcher are integral components of the research process.

Dedra Hafner (2008) explored barriers such as those above by using a phenomenological approach to show how 7 students in a 4-year PSE program helped to transform the campus through their involvement in academic, social and community roles in college. Through student interviews, reflection papers and focus groups including students, peers and faculty, Hafner found a number of examples of how full inclusion positively impacted student identity and self-determination, as well as peer and faculty attitudes and practice. In a similar phenomenological study of inclusion for students with intellectual disabilities in a PSE program, Obrien, et al. (2009) used focus groups, reflective journals, photovoice, and graphic representations of person-centered planning meeting outcomes to examine the development of student identities, including student as

friend, student as advisor, student as learner and student as dreamer. The strength in this study is in the variety of methods used to collect data, an important consideration for all qualitative research involving individuals with alternative communication styles.

In 2001, Grigal, Neubert and Moon stated,

We know little about the development, implementation, and evaluation of such programs, the instructional practice or curricula used, or the impact of these programs and practices on student outcomes. (Grigal, Neubert & Moon, 2001, p. 245)

They were right on the mark regarding their assessment of the research landscape regarding postsecondary education programming for students with intellectual disabilities. Early studies were, as I stated before, much more “practical” in nature, outlining the history of postsecondary education from the 1970s to the present, the status of the current, limited pool of options, as well as the connection to social movements calling for an expansion of those postsecondary options (Neubert, Moon, Grigal and Redd, 2001; Grigal, Neubert, & Moon, 2002; Migliore, Butterworth & Hart, 2009; Grigal and Hart, 2010).

After the post-Reauthorization of Higher Education Opportunity Act program development “boom” in 2008, we saw a related increase in research focusing on survey and program descriptions highlighting basic programmatic characteristics, recruitment and admissions, course access, employment strategies, etc. (Grigal, Hart & Weir, 2012). As of 2009, Grigal, Hart & Weir

(2012) had surveyed as many as 149 programs across 39 states, and PSE programs across the nation offered descriptions of their 2-year, and less frequent 4-year certificates at community colleges and universities, identifying themselves as substantially separate, mixed programs, or fully inclusive/individualized programs (Grigal, Hart & Weir, 2012; Hafner, Moffat & Kisa, 2011; May, 2012; Folk, Yamamoto & Stodden, 2012; Hendrickson, Busard, Rodgers & Scheidecker, 2013).

There are currently well over 200 PSE programs available to students with intellectual disabilities in the US, and with the increase in options, there also comes an increased need to look at how programs are evaluating outcomes and the efficacy of their supports/programs. The majority of studies looking at outcomes for college students with intellectual disabilities focus on employment outcomes (Migliore, Butterworth & Hart, 2009; Smith, Grigal, Sulewski, 2012; Grigal and Hart, 2010; Grigal and Hart, 2013) There are limited studies that have used student feedback to identify more comprehensive ideas about outcomes (Folk, Yamamoto & Stodden, 2012; Papay and Bambara, 2012), but in general, I am in agreement with Hendrickson, et al (2013) who urge us to expand research because,

There is a dearth of empirical data on the immediate and long-term outcomes of program components and postsecondary programs in general... There is an urgent need for both qualitative and quantitative research to examine the many questions that must be addressed to guide policy makers, administrators, educational practitioners, and family members/guardians. We strongly encourage individuals and institutions to

work together to establish evaluation designs and research agendas in concert with the development of postsecondary education options for students with ID (p. 196).

Grigal, Hart & Weir (2012) reflect the same concern in their call for intervention studies that explore the impact of PSE practices on outcomes as well as more longitudinal data on PSE and post-PSE outcomes beyond employment. I think, however, that we need to be cautious as we move forward, in making sure that we do not exclude the voices of the very people for whom we are advocating in our attempts to race to the top with our own research agendas.

Historical Backdrop- Special Education

It is important to have a sense of the history of specialized education in the US in order to fully understand the ways in which students with ID/DD have traditionally been perceived and/or treated within the educational system, as this is likely to inform how they are or are not welcomed in higher education. Special education did initially originate as a challenge to the status quo, from the progressive notion that people with disabilities should be treated as human and with greater equity, however it has become very rigid and prescribed in its form over time.

Educational historians Lucinda Spaulding and Sharon Pratt (2015) have identified three major eras in the history of special education: early reform (1800-1860), stagnation and regression (1860-1950) and Contemporary reform (1950-present) (p. 92). In so doing, they have provided a helpful framework that outlines

the history of special education in the United states, and one which I will use to illustrate this step-taking. The early reform period involved challenging centuries old beliefs that viewed people with disabilities as less than human, deviant, “qualitatively different” and something to be hidden from the public eye (Carey, 2009; Trent, 1994; Winzer, 1998 as cited by Spaulding & Pratt, 2015). Children were hidden away by families to avoid stigma, “charity” was given to “salve the consciences of benefactors” rather than in the best interest of recipients, and ownership of “knowledge” was generally associated with “humanness” (Spaulding & Pratt, 2015).

By the 19th century however, advances in philosophical thought, medicine, science and economics sparked a change in attitudes that resulted in more protections for people with disabilities. During this era, the common school movement began, where all children were to be educated in the “common schoolhouse” to create a “common culture and reduce social conflict” (Spring, 2011, p. 80) Inquiries about the “essence of human nature” sparked an interest in education for people with intellectual disabilities (p. 95), and the industrial revolution was equal opportunity in its attempt to transform all its citizenry from consumers into producers (Spring, 2011, p. 95).

Even with this movement towards the valuing of people with disabilities, early programs for children with physical and cognitive disabilities were often located in hospitals, in separate classes where “struggling learners could develop at their own rates, with the goal of ‘catching up’ and rejoining the general class”

(Baglieri & Shapiro, 2012, p. 186). This belief in the need for a specialized settings fueled that separatist view where “student should master and be able to express or perform each component of a skill before moving onto a sequential step” resulting in students getting “trapped in special education” (p. 186). This development, although it called for the segregation of students with disabilities, was still an advance from the dehumanization of people with disabilities that characterized the early 20th century.

During what Spaulding and Pratt call the era of stagnation and regression, the rise of empiricism and economic pressures resulted in a return to the pathologizing of disability. Mental disability would be theorized to be the principal factor in criminal behavior and alcoholism, and as a defect to be tested for and eliminated (Spaulding & Pratt, 2015). Darwin’s conclusions about the animal world would be devastatingly applied to people with disabilities, and with Oliver Wendell Holmes’ crusade against a “contaminated species” that was a threat to society, the stage was set for eugenics and state-sanctioned “genocide” (Spaulding & Pratt, 2015). In this climate, and as states began to pass laws calling for compulsory attendance to common schools, children with disabilities were kept out of school or segregated so as not to negatively influence other children (Spaulding & Pratt, 2015). A pattern also emerged during this time, where black and brown students, who were labeled as “culturally deprived” were tracked into classes with students categorized as “mentally retarded” and “emotionally disturbed,” heralding a new era of “racial containment” and “parallel

education” in schools that is still in operation to this day (Baglieri & Shapiro, 2012, p. 187).

After World War II, as the United States attempted to distance itself from eugenics practices that characterized the Nazi regime, and through a combination of medical advances in treatment and parental advocacy and lobbying, attitudes about disability shifted once again (Spaulding & Pratt, 2015). As a result of fights for equal rights by advocates like the Kennedys, schools were mandated to provide education to all children through laws like the Individuals with Disabilities Act (IDEA) in 1975 and there was an increase in special education services with a focus on providing “free and appropriate education”(FAPE) in the “least restrictive environment” (LRE) possible through Individualized Education Plans (IEPs) (Spaulding & Pratt, 2015).

This increase in legislation and programming also highlighted philosophical differences in approach however, as inclusion into general education classrooms through the Regular education Initiative (REI) took hold in opposition to the segregationist advocates who argued that children with ID/DD cannot benefit from general education classes, or somehow are too burdensome for the teacher (Spaulding & Pratt, 2015). A debate began to coalesce, between those who conceptualized inclusion as a moral imperative, “ aligned with civil rights and a humanistic perspective on the role of schools in society (Gallagher, 2001 as cited by Baglieri, p. 188) and those who felt it necessary to wait for an

empirical body of research demonstrating positive outcomes for students with disabilities before moving toward 'full inclusion' (Kavale, 2002).

Researchers like Ashby (2012) and Slee (2001) argued that special education's "traditional formulations of disability as defective individual pathology" needed to be challenged and re-evaluated in terms of "political, cultural and historical specificity" (Slee, 2001, p. 170). Ashby expressed concern about teacher preparation programs that are anchored in the "medical model of disability" and position disability as a "deficit that can be addressed through identification and remediation" (Ashby, 2012, p. 91). Slee (2001) echoed this concern regarding traditional special education programming, asserting that efforts at inclusion were "appropriated" by "quasi-medical pathologies of defectiveness" (p. 168). Both authors connected the vocabulary of "defect" to oppressive practices that continued to segregate and dehumanize students with disabilities.

These voices however, have not historically been the loudest voices in the special education debate. Those belong to the traditionalists, or those who see the purpose of special education as a process of figuring out how to remediate the learner or the "make the child right." These are scholars and educators who "generally accept the categorical definitions of disability proffered by special education systems that, in turn, displace the lived experience and thus diminish understanding disability as part of the larger human experience" (Ware, 2009, p. 111). They represent the most widely accepted perspective of this era;

an era which called for segregation and isolation of students with ID, oftentimes “in basements, down dark hallways and in former closets...” (Winzer, 1993), with little or no acknowledgement of the ways in which disability “permeates the everyday schooling context in multiple and complex ways” (Ware, 2009, p. 111). This debate is important to acknowledge as “inclusion” efforts continue to proliferate on college campuses. The vestiges of traditional thinking are present among faculty, staff and students in higher education, and even those who identify with inclusion often unwittingly subscribe to the same process of labeling that effectively others.

Critical Special Education and Challenges to the Medical Model

Ellen Brantlinger’s (1997) analysis of special education literature, speaks to this regime of traditionalists who have long manipulated the field’s official knowledge base, a body of literature which in her words,

remains grounded in a functionalist behaviorist tradition that views truth as singular, relies on microscopic views of human nature, employs social science methods, and through analysis of causal factors places a high premium on prediction and control to yield law-like generalizations (Ware, 2009, p. 107).

Scholars like Brantlinger and Burton Blatt, who is widely known to have initiated a more critical approach to special education, were often silenced by the heavyweights within the traditionalist, empirically focused special education camp, but still managed to spark a “critical special education” movement that

critiqued the “normative practices, beliefs, and assumptions about disability outlined in the bulk of the traditional special education literature” (p. 104).

These scholars challenged the unquestioned acceptance of a medical model which had historically been at the foundation of all “ideology, history, social and political assumptions about disability” (Ware, 2009, p. 111). Linda Ware (2009) describes critical special education as occurring in four waves: 1) late 1960s and 70’s-initial discontent with the technical, scientific approach, and challenges to assessment and labeling, 2) 80’s- support for holism and the sociological perspective, 3) 90’s- focus on interpretivism, activism and post-modernism and 4) 2000 to present- a move towards disparate, interdisciplinary scholarship, emergence of disability studies in education (DSE) (p. 107).

During the 1990’s, disability research that challenged the medical model by using a post-positivist lens began evolving in the United States as well as Europe, Australia and New Zealand; a critical response to social science’s proclivity towards finding proof generated by objective, truth-finding (Connor, Vale, & Halle, 2015, p. 2). At this time, the Coalition for Open Inquiry in Special Education (COISE), consisting of scholars like Scot Danforth, Ellen Brantlinger, Phil Ferguson, Lous Heshusius, and Chris Kliewer was formed, making a case for “open inquiry” or an “expansion and diversification of what was considered legitimate and valuable writing within special education publications” (Connor, Vale, & Halle, 2015, p. 3). Ware (2009), joined scholars like Ashby, Slee, Blatt, and Heshusius, who spoke forthrightly about the need to challenge special

education's long-standing model for "prevention/treatment/remediation/ measurement" and its conceptualization of disability as a story of pathologizing difference in pursuit of normalization" (p. 105).

Slee (2001) went a step further, to connect inclusive education to "cultural politics" by stating that while special educators are "seldom likely to place issues of class, culture and ethnicity, sexuality, bi-lingualism, and so on onto their agenda for educational inclusion" there is still a tendency to "pull up short before disabled students when arguing for representation of diversity in schooling" (p. 168). He asserted that,

Special education stumbles into the reductionist trap of promoting inclusive education according to the technical assimilationist imperative of making 'defective' kids fit the school, as it is. Inclusion and social justice with it, cannot be reduced to absorption (p. 170).

His writing positions the call for inclusive education as a project of "reconceptualization and radical reconstruction" (p. 11) to ensure that students with disabilities are valued, recognized and given access to a broad variety of resources and opportunities.

Special education's historical role in advancing this concept of normalcy cannot be overstated. The meritocratic creed that is at the center of the American educational system, serves as the determining factor for how individuals with disabilities are measured and found wanting. Scholars within the traditional special education community like Kenneth Kavale and Steven Forness (2000)

assert that the only way to determine educational policy for students with disabilities is to rely on scholarly rigor and measureable scientific evidence. They question the validity of conclusions made by scholars who claim that students with disabilities have a right to full inclusion in educational settings, who have not used neutral and randomized methods in their experimental designs (Kavale & Forness, 2000). Kavale, who has been praised for his “staunch, even dogged demand for high scientific standards in learning disabilities research and practice” (Regent University, 2015), reflects special education’s characteristic call for assessment, intervention, diagnosis and classification, as well as its penchant for looking for ways to fix disability problems.

In Nirmala Erevelles’ (2009) compelling analysis of the history of American education and how ability has been used as a category to reinforce hegemonic ideologies she describes mass public schooling as a response to “the turmoil” of the Civil War, “the subsequent industrialization, urbanization, and rapid economic growth that ensued; and the increasing influx of immigration to the United States” (p. 76). Public education’s focus on the relationship between disability and other social differences, according to Erevelles, and its effort to recreate an integrated and disciplined society, obscures the ways in which the “democratic ideology of the common school” has been incompatible with the “social reality of class structure” (p. 77). Erevelles highlights how, in spite of legal mandates for desegregation, the disability category has been used to support the regular and special education delineation, and how students who

have been marked by race, class and gender have been relegated to “lower tracks within the educational matrix” that reflect similar placement within the socio-economic “order” (p. 77).

Even as critical scholarship began to emerge within special education and as the field of disability studies itself evolved, Ware (2009) points to a noticeable lack of “centering” of a disability perspective within general critical theory. This failure to consider disability related issues, Ware contends, is a reflection of the fact that disability “occupies little more than sideshow status extraneous to the “big tent” concerns of critical theorists” (Ware, 2009, p. 104). It is this gap that the field of disability studies works to address, by taking a critical, interdisciplinary approach that draws from a variety of scholarly genres to “re-create a developed portrait of disabled people across histories and cultures” (p. 13). In this way, DS differs from special education in that it “speaks to shared humanity” rather than focusing our differences that “estrangle us” (p. 103).\

Disability Studies (DS) and Critical Disability Studies (CDS)

As with critical special education, the DSE tradition has historically and politically resisted the individualized, medical model of disability, preferring instead those interpretations that have focused on “collective sociopolitical issues”(Gabel, 2009, p. 5). Gabel (2009) argues that

The danger, of course, is in the misapplication of the medical model to the social contexts of disability. Some of these misapplications include: using the medical model to diagnose, prescribe, and treat “conditions” that are the result of institutionalized oppression; adhering to the medical model’s

emphasis on individual pathology while ignoring social pathology; reproducing the myths used by the medical model (eg, IQ) to stigmatize individuals and groups with labels; and dehumanizing individuals with functional limitations (Gabel, 2009, p. 8)

As Linton (1998) points out, Disability Studies as an interdisciplinary field, has provided a platform for organizing the scholarship and knowledge base that challenges assumptions of the medical model, and explores disability as a “social phenomenon” (p.117). She goes on to say that DS “adds a critical dimension to thinking about issues such as autonomy, competence, wholeness, independence/dependence, health, physical appearance, aesthetics, community, and notions of progress and perfection” which is significant because these are issues that “pervade every aspect of the civic and pedagogic culture” (Linton, p. 118)

Linton offers the following four main areas of research that she believes will help DS be an effective interdisciplinary field which is capable of bringing “multiple perspectives to bear on the phenomenon of disability and can present disability as an organizing principle used to formulate questions, hypotheses, and a coherent knowledge base”(p.125).

1. Theories across the curriculum that “conceptualize disabled and non-disabled people as complementary parts of a whole integrated universe” (p. 120).

2. Articulation of how and in “what areas of theory centering disability perspectives can be advantageous for knowledge development in all content areas” (p. 121).
3. Disability has traditionally been housed in the “applied” fields, wherein the “vast majority of work that explains and elaborates on the social-political paradigms is not found in that knowledge base”- should be more interdisciplinary, “grounded in the humanities and social sciences (p. 123).
4. Attention to the vast realm of meaning- making that occurs in metaphoric and symbolic uses of disability (p. 125).

These areas of research help to set the stage for the discussion of critical scholarship within the field of education.

Disability Studies in Education (DSE)

Critical scholars in education apply the lens that Linton describes in their evaluation of the educational system, pedagogy and practice. There is generally a focus on the social model, and how it resists oppression, political and economic exclusion and stigma based on the experience of “disablement” strives to get as close as it can to explaining the “reality of disabled people” (Gabel, 2009, p. 8). A goal that is problematic in my mind, as laid out by Gabel, given its reductive nature, but an impetus that is nonetheless important in its effort to close the gap between theory and what “disabled people need to know in understanding and changing their lives” (p. 6). Gabel and other critical education scholars contend

that this important perspective is missing from educational studies, and stress the importance of DSE as a scholarly approach. She goes on to compare DSE to philosophy of education or history of education and says that DSE can be defined as the use and application of disability studies assumptions and methods to educational issues and problems (p. 10).

Nirmala Erevelles (2009), speaks to the ways in which disability, defined as a social construction where “people experience processes of power directed at their bodies” (p. 79), is conspicuous in its absence in the “scholarship of prominent educational theories (p. 67). In her 2014 analysis of Price’s (2011) study on mental health within higher education, Erevelles generates three themes that are essential for a critical evaluation of disability within education, 1) deconstruction of normalcy/rationality rhetoric, 2) linking alienation and colonialism to the medical model, and 3) acknowledgement of “mental difference” in ethical contexts (Erevelles, 2014, p. 169-171).

As Erevelles uses Price’s work through these themes, she challenges the notion that academia is a space of rationality, asserting that those bodies who do not meet “deeply entrenched” ideas about autonomy and coherence are considered to be outside of the norm, and therefore not an appropriate fit for the “hallowed halls” of higher education (p. 68-69). She challenges medical diagnosis that is used to “contain and control” students who do not “function” within the same normative framework as their peers, linking it to experiences of colonialism and alienation (p. 170). Erevelles lastly critiques an “ethics of autonomy” within

higher education, that denies the power of interdependence between students with and without disabilities (p. 171). I find Erevelles' and Price's critical analysis of the intersection between disability and academia to be instructive in looking at the ways in which PSE requires attention to the ways that theory and lived experience relate. For students whose perspectives have been 'silenced' or "ignored," this critical approach is important.

This need is what makes Allan's (2014) assertion that there is a global phenomenon wherein teacher education programs are reducing critical, theoretical content from coursework, so troubling, as well as his contention that texts on educational research do not generally acknowledge the intersection of theory, philosophy, praxis and material experiences (Allan, 2014 p. 181-182). Bowles and Gintis (1976) argue that by using the concept of intelligence/ability to "legitimate racial, gendered, and class inequalities in both schools as well as society at large" educational institutions imply that there is indeed a relationship between disability and other categories of difference like race, class, gender and sexuality (Erevelles, 2009, p. 81).

Critical DSE questions the construction of such problematic categorizations, and not only challenges the divisive labeling that is endemic to special education, but also challenges contemporary inclusive education as it attempts to assimilate "defective students into the normal educational environment (Allan, 2006; Slee, 2001 as cited by Ashton, 2014, p. 47) and it foregrounds "the need to adapt social discourses and material environments to

ensure equity for folks with diverse abilities (Palmeri, 2006, p. 50) . “Inclusive education is not an endpoint, goal or option” Ashton says, “rather it is a prerequisite of democratic and socially just education” (p. 47). I find Erevelles (2000) call for creating theories that frame people with and without disabilities as “integral, complementary parts of a whole universe” as well as her call for critical research on “practices that divide communities along disability lines” to be critical ones (p. 26), particularly in light of special education’s tendency to “conceptualize disability as a deficit, something absent, suggesting an incomplete human who needs to be fixed, cured, remediated, and shaped into the mold of normalcy at all costs” (Connor, Vale, & Hale, 2015, p. 1).

This backdrop is particularly important as we begin to consider the impact students with ID begin to break through higher education barriers that give them access to the “ivory towers.” The long history between these students and the educational system has set the stage for how they will be met by peers, faculty and administrators on college campuses. Stigma about disability runs deep in this country, with a comparatively short time of advocacy and acknowledgement of equal rights. It has only been within the past 10 years or so that legislative advocacy has provided federal guidelines for ensuring IHE participation in these changes.

Black Disability Studies

The recent trend in viewing disability through an equal rights lens that acknowledges their integral place in the “whole universe” will require a more

intersectional approach than we have generally seen, as Chris Bell critiqued earlier. Black disability studies (DS) itself developed as a response to the “invisibility” of black voices and bodies within the “disability rights” movement that was predicated on the “individualistic perspectives of white scholars” (Jarrett, 2015, p. 6). Today the disability community still has a difficult time “reaching people outside of dominant culture (Moore, 2015, p.4) and too frequently disability in Black communities “becomes concealed under the blanket of homelessness, substance abuse, violence and poverty” (Jarret, 2015, p.6). The social model of disability requires a move past “race and class neutrality” to encompass the diversity of lived experiences that “shape the making of disability” (Nishida, 2015, p. 9).

Black DS shines the light on the collusion of racism and ableism not only in the lives of black people with disabilities but those without as well. It prioritizes an analysis of this intersection of race and disability and how lived experiences parallel each other in relation to “social services, representation, social attitudes, violence and access to technology” (Schalk, 2015, p. 11). This analysis is not presented as a comparison of oppression, but as a critical examination of life at this intersection, that also has significance as a lens for ALL black folk. Sami Schalk (2015) frames this well by looking at how disability discourses have been used to “deny the rights and humanity of many groups of people throughout history” including black people. The central element of Black DS, the analysis of the intersection of race and disability, needs to be included in any pedagogy that

seeks to shed light on the intersection of education and power inequities in this country.

Feminist Disability Studies

Feminist disability studies (FDS), like Black DS, speaks to the need to view disability through multiple lenses and/or identities. Feminist theory, the foundation for FDS, has evolved over what is traditionally described as three waves of thought, focusing respectively on injustices enacted upon the female body, the right to live an “educated and economically powerful life”, and an acknowledgement of the “range of sexual identities/ways of being/physicalities/psychologies” (Dadd, 2011). It is collaborative, interdisciplinary and sensitive to how “the representational systems of gender, race, ethnicity, ability, sexuality, a class mutually produce, inflect and contradict one another” (Carter, 2015, p. 11). I acknowledge that this is a cursory description of an involved evolution of thought over time, but for the purposes of this study, I will be concentrating on the contemporary “pivot points” of feminist thought that Julia Dadds describes as reflexive historicity, lived experience and hidden structures, dialogic engagement with the margins, embodiment and interdependence (2011, p. 177).

Feminist disability theory introduces the disability continuum as a representational system into the mix, in an attempt to expand “current notions of cultural diversity (Carter, 2015, p. 11).” As such, this continuum is reflective of the pivot points that Dadd highlights, in that the experience of disability is lived in

unruly bodies that are traditionally shifted to and engaged from the margins. Feminist disability studies pedagogy (FDSP), reflects practice that blends “the ways dis/ability intersects with other vectors of power and oppression to inform how we teach and learn” (Carter, 2015, p. 11). FDSP utilizes principles of Universal Design (UD) to create accessible classrooms for all students, not as an isolated “best practice” but as an integrated element of an overall approach that moves beyond inclusion as a goal, towards “shifting the pervasive and intersecting forces of inequality” (p.11). FDSP’s focus on embodiment, lived experiences and interdependence are particularly salient to disability discourse, specifically for students with ID, whose experiences “ways of knowing” are repeatedly discounted and dismissed within higher education.

The backdrop provided in this chapter was designed to illustrate the link between the history of education for students with disabilities and contemporary postsecondary engagement, as well as situating postsecondary programming within theoretical traditions like Disability Studies and DS in Education and others. Chapters 3 and 4 will further illustrate how these connections and traditions have informed and provided direction for this research

CHAPTER III

RESEARCH METHODOLOGIES

We often lament the poor post-school outcomes of students with intellectual disabilities. However, we never seem to make the connection that the system does not support students with intellectual disabilities to learn *anything* after they leave high school. (Grigal & Hart, 2010, p. xiv)

In order to understand the significance of the research approach used in this study, it is essential to understand how ideas about disability have been conceptualized, perpetuated and researched in the US. In this chapter I provide an overview of the ways in which disability has been traditionally researched in the US, to highlight and position the importance of community engaged research as a step forward within that larger framework.

Traditional Approaches to Disability Research

Traditional approaches to disability research reflect the ideological push in the US, for objective, scientific inquiry that relies on a norm or as Rioux says, on empirical questions that “are driven by these implicit normative premises, despite claims of objectivity so readily embraced by empiricists (p. 102), that is the medical model approach. Rioux (1997) argues that “germ theory” is at the foundation of this *bio-medical* approach to disability, which supports the assumption that “disability is caused by a mental or physical condition that can

be prevented or ameliorated through medical, biological or genetic intervention” (p.103). This emphasis on the science of diagnosis and assessment results in what UPIAS has described as “panels of professional people coming around with tape measures...to perpetuate the stranglehold the professions have over disabled people”(Upias,1972, p. 8). They go on to say,

The scene facing every physically impaired person, then, is of an army of “experts” sitting on panels which are set up all over the country. These “experts”, armed with the latest definitions and tests for measuring, will prod and probe into the intimate details of our lives. They will bear down on us with batteries of questions, and wielding their tape measures will attempt to tie down the last remaining vestige of our privacy and dignity as human beings (Upias, 1972, p. 17).

In this world, disability is seen through the positivistic lens of diagnosis and evaluation, as an “anomaly and social burden” and intervention is framed as an individual issue/activity/responsibility (Rioux,1997, p. 103).

This is a tension that our program struggles with regularly. There is an intense pressure from families, from educators and administrators, from the students themselves sometimes, to identify, diagnose, treat, and fix. Students are asked to be quiet, not ask so many questions, stop staring, be still, don’t get too close, don’t be too friendly, ultimately, to “act like everybody else.” This connects directly to what Rioux calls the *functional* approach to disability, which assumes that disability is seen as a deficit that “stems from an individual condition or pathology” (p. 104).

The focus is not medical intervention here, but rehabilitation. It looks at ways of “treating the functional incapacity through amelioration and enabling strategies to assist people to develop their potential” (p.104). “To treat this functional incapacity,” Rioux (1997) says, services are offered to individuals to help them become as “socially functional as possible” to come as close as possible to the functional “norm” (p.104). It is my experience that this is what people expect of PSE programs, this specialized treatment focus designed to help students function like their peers. I think that there is a significant need for research in the field that explores providing support to students and campus communities in a way that challenges this race for “normalization.”

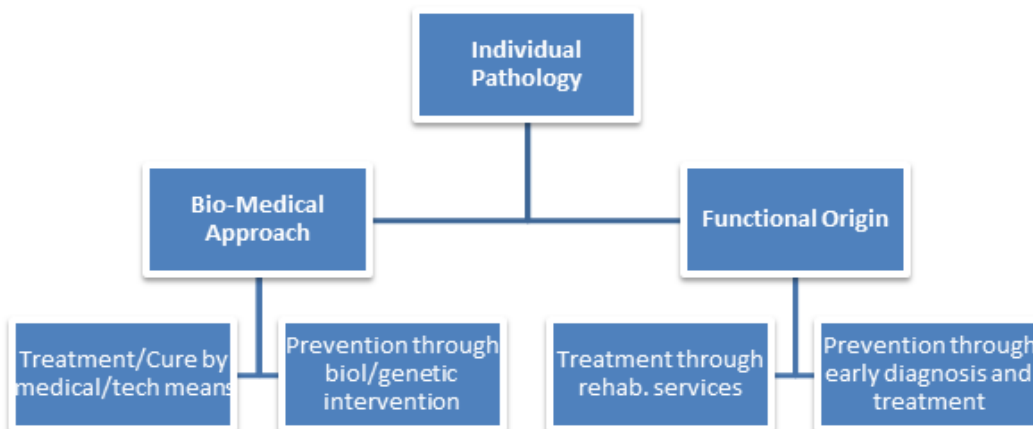


Figure 7. Scientific Formulations and Treatment of Disability (Rioux, 1997, p.104)

Like Kanter's alternative disability models, Rioux identifies "social" pathology approaches that take environmental and situational factors into account. These approaches are a reflection of the social model, as they focus on disability as a minority identity that "is a product of disabling social and built environment" (Siebers, 2008, p.3). Within the social pathology framework, Rioux defines the environmental and human rights approaches to disability as those that see disability as "difference rather than anomaly," and do not take an individual approach to resolving disabling forces (Rioux, 1997).

When I first started working in this program, we were more closely aligned with the individual pathology approach, i.e. supporting students to "fit in to the system," as I said before. Although we still struggle to challenge this thinking, we are much more closely aligned with the social pathology approaches at present with the critical disability model introduced in the conclusion. We see the significance in research that addresses societal, cultural and other political forces that negatively impact folks with disabilities in contrast to research that measures strategies for "treatment." Research that reflects the *environmental* approach as Rioux conceptualizes it, demonstrates how failure to accommodate difference "exacerbates the impacts of disability." (Rioux, 1997, p.105). This impact is addressed by ensuring that individuals are able to self-direct their own services and by attempting to prevent the disabling conditions through the elimination of "social, economic and physical barriers" (p.104).

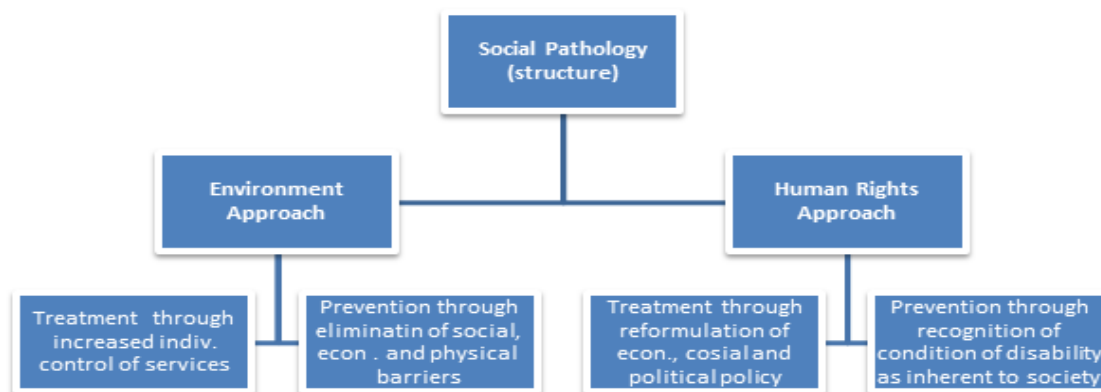


Figure 8. Social Formulations and Treatment of Disability
(Rioux, 1997, p.104)

This approach resonates with our program as we work with students who are learning to self-direct and identify and strategize around barriers, and with its emphasis on self-determination, this research study itself could be classified as the environmental approach.

Our research also reflects qualities associated with the *rights-based* approach, which looks beyond “particular environments to focus on broad systemic factors that keep certain people from participating as equals in society” (Rioux, 1997, p. 106). Like this approach, our program and research philosophy asserts that people with disabilities represent “wide variations in cognitive, sensory and motor ability” and are valued members of society (p. 106). Research in this arena focuses on public policy that centers equality and the right to access supports and services that allow for self-determination (p. 106). We do significant

work in this area, and I would argue that there is a gap in the research regarding scholarship about how PSE programs are impacting local and national policy.

Rioux (1997) goes on to say that there is nothing inherently wrong with any of the approaches described here, including the medical approach. The danger, he says, lies on relying on any one perspective (p. 106) . He makes a good point when he says that for those who reinforce the social model, it is still crucial to understand the forces that drive research from the bio-medical perspective, such as “neo-conservative economic agenda, utilitarianism, culture of objectivity and positivism” (Rioux, 1997, p. 107). He goes on to say,

In times like the present, when social policy is driven by economic neo-conservatism (Drache, 1995), funding is much more likely to be allocated to research that reinforces cost-savings. Another line of inquiry supported in the reductionism of the new economic environment is on research in ways to eliminate individual differences that cause inefficiencies and dysfunctions in the global economic system as it is presently constituted. Comparatively few resources are invested in how to reorganize economies to integrate human differences, to empower marginalized groups and to ensure civic inequalities (Bowles & Gintis, 1986). In a neo-conservative economic policy climate, researchers are pressured to look for cost-savings. (p. 107)

In a society whose economic and social well-being is believed to be reliant on the premise of utilitarianism, or the responsibility to ensure that scarce resources go to those who “benefit the most,” objectivity is a key cultural element that drives the research agenda (p. 108). The resulting focus on empiricism and/or positivism has led to a suspicion of more “inductive and qualitative

approaches” Rioux says, (p. 108) and conditions where fact is valued more highly than the judgment of advocate. Oliver (1992) states the following,

Up until now, there is no doubt that social research has been dominated by positivism... These assumptions consist of the following; a belief that the social world can be studied in the same way as the natural world- that there is a unity of method between the natural and social sciences; that the study of the social world can be value-free; that, ultimately explanations of a causal nature can be provided; and that the knowledge obtained from such research is independent of the assumptions underpinning it and the methods used to obtain it (Oliver, 1992, p. 106).

He echoes Rioux’s concern about this “positivistic consciousness and hierarchical social structure” that gives elites the upper hand in setting the agenda for disability research (p.102).

UPIAS has challenged the bias of these small groups of elites who, they say, have been more concerned with the effects of disability, rather than the actual cause, limitations that have been imposed by society (p.5). The funding of research and policy that is dependent on determining degrees of disability results in a situation where disabled people have a “vested financial interest” in presenting disability as their main asset (p.17). This bias, according to the union, “underlines the imperative need” for disabled people to be valued as their own experts and to regain “authority over their own social interests” (p. 5). Corbett (1998) asserts that the opinions of professionals have long been listened to with more attention than the voices of disabled people, who are viewed as “inadequate because of personal deficits,” and that generally professionals who

speak of empowerment mean on their terms and using their own perceptions of what is appropriate” (p. 54). As Oliver (1992) says, disability research is an opportunity for disabled people to challenge the oppression that they experience on a daily basis, and for the experts to join them as they refrain from using their skills and expertise in ways that “disabled people find oppressive” (p.102).

Oliver (1992) highlights the words of Patti Lather as he goes on to call for a “newer paradigm (critical inquiry/emancipatory research)” which has a “different view of knowledge (theory),” that focuses on the “lived experiences of progressive social groups” (p.107). “To be adequate to the task of the changing the world,” theory, as Lather states, has to be “open-ended, nondogmatic, informing, and grounded in the circumstances of everyday life” (Lather, 1987, p.262, cited by Oliver, p.107). Emancipatory research, according to Oliver, is about people empowering themselves, confronting social oppression, and the role that research can have in that process (Oliver, 1992). He says,

This does mean that the social relations of research production do have to be fundamentally changed; researchers have to learn how to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever ways they choose. The task for emancipatory research is not, as is sometimes implied, to help the researched to understand themselves better, but to develop its own understanding of the lived experiences of these very subjects, (Oliver, 1992, p. 111).

In an environment where the bio-medical approach to disability research influences disability policy and practice (Rioux, 1997, p. 103), Oliver’s call for emancipatory research is unfortunately not the predominant one. In accord with

Oliver (1992) and scholars like Grigal and Hart (2010), whose work has illustrated that students with ID are essentially invisible when it comes to research efforts regarding disabled students, I see this study as an important opportunity to claim space within disability research and scholarship.

Emancipatory Research Methods

Within the DSE tradition, research is generally approached from an emancipatory standpoint, both in a broad sense to mean a number of methods that assume that people with disabilities are the experts on their lives and the experience of living with a disability, as well as a more specific method of “critical social research” that has roots within the feminist tradition and focuses on the facilitation of “a politics of the possible by confronting social oppression at whatever level it occurs” (Oliver, 1992 as cited by Watson, p. 95).

From this tradition, emancipatory research has been envisioned as a way to combat the divide between “the researched and the researcher” as Watson (2012) has said. There is a focus here on leadership and involvement in the research process by the group in whose interest research is being put into action (Gabel, 2009, p.9) as well as the acknowledgement of “alternative oppositional intelligibilities” created by students who have heretofore been labeled as marginal or deviant (Erevelles, 2009, p. 70). It is ultimately concerned with “full participation in society where the work toward social change is led by those who are, themselves, oppressed” (p. 9). Once again, though, notwithstanding the emancipatory possibilities that these studies promise, the voices of disabled

students as oppositional subjects/agents have remained conspicuously absent in this diverse array of counter-narratives (Erevelles, 2009 p.70).

In the mid-80's, a number of scholars began to develop "disability methodology frameworks" to address the absence that Erevelles references, paralleling participatory work being done by other critical theorists, women scholars and writers of color (Stevenson, 2010). In 1991, an emancipatory disability framework was outlined by Oliver Barnes, including the following core principles: control of the research process, accountability to disabled researchers, practical outcomes, support of the social model of disability, methodological rigor, decision making in design, and the valuing of lived experience (Stevenson, 2010). Similar principles have been identified by Whaley Hammell (2007), who provides insight in to the occupational therapy perspective, with the addition of points related to respect, reflexivity and the centering of priorities of disabled scholars (p. 367).

As definitions of emancipatory research paradigms are discussed in the following section, it is helpful to keep the frameworks provided by Barnes and Hammell in mind. The principles that they have recommended for the research community were certainly an integral part of decision making regarding what was going to be the best methodological match for this study. I argue that these frameworks, in concert with black feminist thought, black disability studies and feminist disability studies, provided a clear methodological pathway that led me to community engaged research (CER).

CER is one of several methods that fall under an “emancipatory” umbrella, along with emancipatory research (ER), action research (AR), participatory research (PR), and participatory action research (PAR). Although they are presented here separately, they are not always thought of discretely, and are often claimed interchangeably amongst scholars (Flicker, et al, 2007; Lykes & Coquillon, 2006, Smith et al., 2010). Looking at them separately however, helps to illustrate some of the different ways in which emancipatory research can be approached and how community engaged research emerges as the best match for this particular study.

Action research (AR) and **Participatory Research (PR)** are approaches that value the democratic process as a central element for research methods (Lykes & Coquillon, 2006). AR is most associated with the improvement of the “professions,” worker productivity and satisfaction, and with the process of mixing theory and practice in educational settings (Stoecker, 2003, p. 37), and PAR is characterized by “the centrality of social conflict and collective action, and the necessity of changing structures” (Comstock & Fox, 1993 as cited by Stoecker, 2003, p. 37). There is also an aim to ensure that people are involved as “more than just subjects” and are in fact involved in the research process itself (Watson, 2012, p. 97). AR differs from PR in that it does not focus on challenging the “structural antagonism” that exists between groups, and unlike participatory research, it emphasizes collaboration within the status quo.

Participatory action research (PAR), which brings together the praxis elements of action research and the participatory philosophy, is an approach that has been widely used with people with disabilities. Fundamental to PAR are the following elements:

First, that conventional research relationships, whereby the researcher is the 'expert' and the researched merely the object of investigation, are inequitable; secondly, that people have the right to be consulted about and involved in research which is concerned with issues affecting their lives; and thirdly, that the quality and relevance of research is improved when disabled people [sic] are closely involved in the process. (Stalker, 1998 as cited by Watson, 2012, p. 97)

Central to the core of PAR is the idea of co-research that results in the development of "critical consciousness" amongst members of a team that moves back and forth between "education, reflection, investigation, interpretation and action over a period of months or years" (Smith et al., 2010, p. 117).

Community Engaged Research

(CER), also known as community-based research (CBR) is an approach that can be described as a marriage between the two goals of "community development" and "knowledge generation to achieve social justice ends" (Flicker et al., 2007, p. 240). It is a methodology that involves "collaboration between trained researchers and community members in the design and implementation of research projects aimed at meeting community-identified needs" (Strand, 2000, p. 85), a connection between university and communities. Stakeholders are ideally involved in every step of the process, "from identifying the research

question to formulating action proposals that derive from the research results” (Strand, 2000, p. 85).

The definition of community-engaged research that speaks most significantly to me is Randy Stoecker’s (2003) description of it as a method that places “researcher resources in the hands of grass-roots community members” to control the research process (p. 36). In this framing, social issues as understood by the community, are used to define the project and related theories, “undermining the power structure that currently places control of knowledge production in the hands of credentialized experts” and in its most radical of incarnations, effective CER will result in “massive structural changes” that impact “government policy, economic practices, or cultural norms” (p. 36). Berman (2008) connects community engaged and arts based research approaches and describes them as a way to “counter the influence of the competitive, power driven, conflict-ridden organisational processes of the academy toward more consensual and cooperative ways of learning” about phenomena (p. 519).

Each of these models of research described here share common goals of challenging ideas of neutrality and objectivity in research, the generation of knowledge that is of genuine interest to all co-researchers, collective processes of “inquiry that expose ideological, political, and social processes underlying and permeating systems of inequality” (Lykes & Coquillon, 2006, p. 298). Although these are “worthy aims” as Nick Watson (2012) acknowledges, there are also

difficulties that arise with these forms of research, most notably that their “sheer scope makes the translation of such ideals into a research agenda problematic” and that within the field of disability studies, people with disabilities have not *truly* been consulted in the development of research priorities. (Watson, p. 98).

As Swain and French (1998) assert, within the educational context, we must actively seek the “voices” of disabled scholars to ensure that they are “participating in decision-making that will have a real impact on their lives” (p.30). There is a history of this engagement, or lack of engagement in disability politics, that requires us to ask a number of questions of ourselves, highlighted here by Swain and French (1998),

1. Who is this work for?
2. What right to I have to undertake this work?
3. What responsibilities arise from the privileges I have as a result of my social position?
4. How can I use my knowledge and skills to challenge the forms of oppression disabled people experience?
5. Does my writing and speaking reproduce a system of domination or challenge that system?
6. Have I shown respect to disabled people I have worked with? (p. 34)

I believe that these questions provide a great road map for those of us who are ready to take action to see that our communities are inclusive, and they have been a guide for me in this research.

As Barnes (1991) says, inclusion as an issue “goes well beyond disablement and is applicable to researchers working with all forms of marginalized and oppressed groups” (Swain & French, 1998, p. 33). This reference to intersectionality resonates with me as an activist and scholar, and I think should be an integral part of any PSE program’s agenda. I have seen many a presentation, and have had many a conversation with other professionals and students with ID, and can count on my hands how many times intersectionality has come to the fore. This is significant area that requires attention from those of us in the PSE world.

The most predominant goal of postsecondary education (PSE) programs serving individuals with intellectual and developmental disabilities (ID/DD) is to empower students in the academic process, as well as to provide opportunities for self-advocacy and self-determination. As these students are learning these skills through their academic programs, empowering them to be fully contributing members of the research team that seeks to understand their experience in the program and encourages them to maintain and establish “powers of definition and decision-making” only makes philosophical and practical sense (Swain & French, p. 31).

This is what makes postsecondary programs like my own such valuable sites for community engaged research efforts. Walmsley (2004) challenges us to listen to the voices of disabled folks and advocates and to “discard our colonizing ways, drop jargon, reject ‘rejecting research,’ and put ourselves and our skills at

the disposal of people with learning difficulties so that they might take their rightful place in charge of the research agenda” (p. 66). Student researchers with ID who help make decisions about research design, who analyze and interpret data and who help determine how research will be used and reported answer that challenge.

Understanding the history of positivism within educational, and particularly within special education research activities greatly impacts the ways in which I am called to do research within the educational field. My epistemological viewpoint resonates with research methods that allow for collectivity, self-definition and which have regard for perspectives/lived experiences of marginalized stakeholders. Research that collaborates between multiple members of community, “validates multiple sources of knowledge,” and has the goal of social change (Stoecker, 2003, p. 35). Community engaged research (CER) is the approach that I think best reflects the frameworks that influence my research position as well as our program philosophy.

When emancipatory, community engaged research is valued and implemented in PSE settings, there should be agreement that the voice of the student must remain at the center and the forefront of research efforts. Given the location of PSE programs, within the higher education environment, collaboration amongst a number of stakeholders, including faculty, students, and community members also becomes necessary. For this reason community engaged research is also an ideal method for PSE research, because even as it centers

student voice, it also acknowledges the impact of the community from which those students must operate.

Within this community engaged approach, which holds such great potential for developing inclusive processes, I think that it is important to return to Erevelles' concern about the uncertainty of communication with stakeholders who may communicate in a broad number of ways and levels of skill. It is here that arts-based research (ABR) methods can effectively come into play. Through the use of drama, art, music, writing, etc., ABR "has the ability to connect on an emotional level with the audience, engaging them in an interpretive process which promotes dialogue" (Fenge, Hodges and Cutts, 2016, p. 2). These connections "encourage capacity" among community members to "'hear' and register the range of emotional responses towards equality and diversity" (Page et al, p. 579)

Arts Based Research

This 50 year tradition, according to Valle (2015), provides scholars with a way of moving beyond traditional models of scholarship and "broadening and deepening the qualitative research paradigm through its experimentation with varied representational methods (Vale, 2015, p. 68)," a paradigm that seeks to "*describe and understand the reasons and meanings that influenced social activity, rather than to explain, predict, and control behavior by means of random selection, comparison groups, and instruments of measurement*" (Alexander, p.

3). Artistic or aesthetic inquiry “fosters the discovery of new ideas and emotions” by “grasping meanings that already exist in a world that lies “outside” of us” through the engagement of a “whole thinking-feeling person”(Alexander, p. 5-6). This engagement encourages a more embodied interaction with research data.

As Gergen and Gergen (2011) example, “The use of theater in communicating about the nature of prejudice... has a far different impact on one’s audience than a graphic or statistical form of representation” (as cited in Fenge, Hodges & Cutts, p. 2). Artistic practices can “help members of organizations remember the emotional quality of lived experience that could not be expressed in their organizational roles” (Page, et al, p.580). Valle (2015) affirms that using artistic processes through arts-based research “can move us closer to realizing the kind of social change advocated by DSE scholars” (p. 67), that the artistic process, the “actual making of artistic expressions in all of the different forms of the arts, as a primary way of understanding and examining experience by both researchers and the people that they involve in their studies” (Knowles & Cole, 2008, p. 29).

Hanan Alexander (2016) contends that “the arts capture the dynamic form of social events in symbolic language, behaviors, sounds and artifacts,” in essence, creating a form of aesthetic inquiry where the researchers/artists “create virtual experiences in language, space, time, or sound so that others can grasp what they perceive directly, through encountering a new work of art” (p. 3). When combined with a community engaged approach, there is potential to

counter the “competitive, power driven, conflict-ridden organizational processes of the academy toward more consensual and cooperative ways of learning” (Berman, 2008, p. 519). Here, I think Berman encapsulates the logic for combining community-engaged and arts-based methods, describing a process that in a sense “democratizes” research. Berman proposes that community engaged research involving the arts is a way to encourage “movement from reflection and theorizing to action” (p. 526).

In this move from theory to action, arts-based methods can be very effective in encouraging young folk and students to “engage in conversations and communities that might otherwise be inaccessible to them” (Fenge, Hodges, & Cutts, p. 3). For students/researchers who communicate in different ways, poetry is one way to present the essences of who they are and/or what they think about an issue or question. More importantly, it provides a method of engagement where “meaning is unlimited and everybody has some” (Brady, 2004, p. 636), honoring a multiplicity of voices and experiences.

Poetic Inquiry

If, as Critchley (2005) has said, poetry represents “life as it is” (p. 189) the use of poetic data analysis is a logical approach to capture meaning and represent that reality by reflecting the “essence of what’s said, the emotions expressed, and the rhythm of speaking” of research participants (Glesne, 2011, p. 250). The use of poetic form gives shape to the uniqueness of student voices

in ways that prose cannot, and although this technique creates a “third voice” that is a combination of the researcher and researched, this singular activity is still subsequently able to highlight a more nuanced voice of the student (Glesne, 2011). As this type of analysis is used to connect data to larger themes, the collaborative process helps to create a “deeper understanding of a metaphorical ‘community’ of experience” (Mears, 2009, p. 9).

I contend that poetry as an alternative method of scholarly expression, and its efficacy in distilling the essence of ideas in combination with a community engaged, collective approach that legitimizes “narratives of individuals with disabilities as scholarly sources of valued knowledge (Couser, 2009) is an effective way of “generating, analyzing, and/or presenting data that emerges from collaboration with the people we engage in inquiry” (Valle, 2015, p. 67). For our program, the ability of poetry to be a “self-revealing, self-constructing form of discovery” resonates with what we hope to see college provide for students (Brady, 2004).

I see the use of poetic inquiry as a critical approach to disability studies in education that is inclusive in the most plural sense of the word, that pushes against institutional barriers that oppress, and that offers a counter-narrative to conventional, hegemonic frameworks within higher education. Connor, Gabel, Gallagher, and Morton (2008) argue much the same when they say, “DSE itself may be seen as a counter-narrative to the prevailing and intertwined hegemonic

discourses of normalcy, deficiency, and efficiency operating in (special) education” (cited by Morton, 2015 p. 198).

CER that involves arts-based methods is “ideally suited to apply imagination, collaboration and scholarship” and “challenges different definitions of what constitutes research” (Berman, p. 526) and as Hesse-Biber and Piatelli (2012) argue, “researchers working with vulnerable populations have been required to find innovative ways to do the work of translation” (p. 506). The coming together of CER and poetic inquiry provides researchers with an inclusive approach and tools that support unruly/marginalized groups in naming themselves, speaking for themselves and participating in “defining terms of interaction, a situation in which we can construct an understanding of the world that is sensitive to difference” (Harstock, 1993, p. 545).

Inclusive Research

Just as there are multiple ways of framing and defining emancipatory/participatory/community engaged research methods, there are a number of ways to conceptualize approaches to inclusive research (Bigby, Frawley Ramcharan, 2014; Walmsley & Johnson, 2003; Turk, et al, 2012; Brooks & Davies, 2008; Chappell, 2000; Atkinson, 2005; Ward & Simmons, 1998; Chapman & McNulty, 2004). Bigby, Frawley Ramcharan (2014) point to a number of these scholars in their comprehensive review of peer reviewed literature on inclusive research. They highlight three main approaches to

inclusive research that have been identified: an advisory approach, a people led approach, and a collaborative group approach.

The advisory approach mainly involves people with disabilities in setting research priorities and design, but lack of control in the other facets of the research process has led to concerns about tokenism (Bigby, Frawley Ramcharan, 2014). According to Bigby et al., the most common people led approaches are emancipatory, participatory and action research which aim to “give control to people with intellectual disability to initiate, lead and execute their own research about issues that are important to them” (Bigby, Frawley Ramcharan, 2014). Concerns with this approach include support that is required from non-disabled allies as well as issues regarding rigor.

Chapman (2005) calls for nondisabled researchers to commit to reflexivity to ensure that they “do not take over and that they remain in a facilitative rather than leadership roles” (Bigby & Frawley, 2010, p. 53). I struggled with this over the course of this research process, both because of my role in the organization and because of my role as a PhD student and lead researcher. I checked in with my co-researchers at every stage, and adjusted my own activities based on their feedback. There were times when I had to let go of my own expectations when they did not align with those of the research circle. From what I observed and experienced, circle members were as engaged in the process as they wanted to be, and were offered multiple opportunities to

participate. I engaged in all of these strategies in an effort to ameliorate concerns like Chapman's, and to foster a true sense of community and collaboration.

Bigby, Frawley Ramcharan (2014) define collaborative group approaches as those that are "partnerships or collaborations in which people with and without disabilities who work together have both shared and distinct purposes which are given similar attention and make contributions that are equally valued" (p. 8). When done correctly, this approach is ideal in that it maintains the "integrity and authenticity" of contributions made by researchers with ID, but is also problematic because it requires a significant output of resources (Bigby, Frawley Ramcharan, 2014).

The community engaged approach that we have undertaken with this research is best described by the third, group centered approach. This approach requires "demonstrable indicators of inclusion" in terms of focus, research questions, design, and implementation (Bigby, Frawley Ramcharan, 2014). Chapter 5, the methodology chapter outlines how our research team worked collaboratively together in each of these areas. The chapter is presented in a journal format that unfolds the process in chronological order, with the goal of inviting readers into our community, so that they can experience our process as it developed.

Before the methods chapter however, I felt it essential to provide a chapter that summarizes important concepts and theoretical approaches that have been

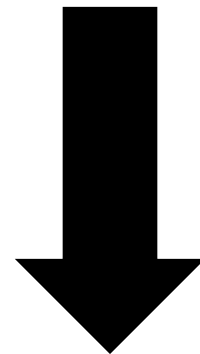
presented in the first chapters, in a way that is more accessible to a wider variety of readers. People with ID have clearly communicated that they find much of the scholarship and research about them to be presented in inaccessible formats. If I am going to lay claim to a positionality that emphasizes the direct involvement of folks with ID in the research process, then I have a responsibility to present that research in a way that the very folks that I am writing about can access. Chapter 4, the visual chapter represents a multimodal approach to discussing the complex ideas that anchor my position and this research, through the use of an infographic format with elements of graphic novel style. Methods for this research study follows in chapter 5.

CHAPTER IV
GRAPHIC GUIDE TO THIS DISSERTATION

This chapter is designed to give an overview of the major concepts at the foundation of this research. Each page stands alone, but together, they should give the reader an understanding of my positionality and the theories/concepts that guide this work.



ENTER



Lets talk about a few important terms before jumping into theory...



PWID=People with Intellectual Disabilities

Presumption of Competence What is it?



PWID need to have other people make decisions for them?

NOPE!



PWID Should be protected from the world?

HUH UH!



PWID are **ABLE** to make their own decisions and have the right to the dignity of risk to experience the consequences of those decisions

**DING
DING!**



This study embraces the idea that folks with disabilities **ARE** competent, and are their own experts (as much as any of us can be) about their lives...

UNRESTRICTED IMAGINATION



MISCONCEPTIONS

LIMITATIONS

BREAKING THROUGH

STEREOTYPES

PRESUMPTIONS

Expanding our
collective ideas
about who
CAN

~~FAIRY TALE~~



This is not meant to
reinforce an idealized
notion that PWID are
special or super...

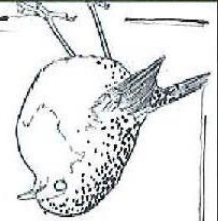
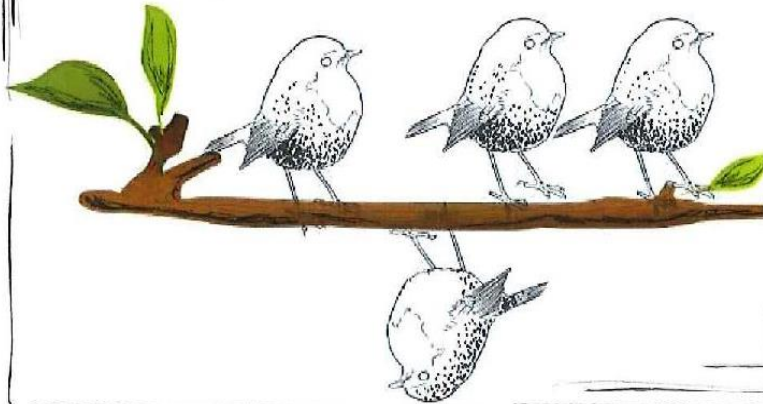


Unrestricting the imagination
just means embracing the idea
that PWID should have
access to a variety of "alternative
possibilities" (MacIntyre, 1999)

Society is in need of an unrestricted imagination to "move beyond the constrained and impoverished view of disability held by many in our society" (MacIntyre, 1999, p. x)

Unruly Body/minds

Bodies and minds that do not conform to the "norm", that disrupt the status quo



This research focuses on unruly bodies and minds in relation to intellectual disability... but there are many ways we can frame "unruliness"

Unruly: not submissive or conforming to rule.
(Oxford Pocket Dictionary of Current English, 2015)

Students...

1. who need more time to process
2. who like to move when they think
3. who use different modes of communication/language
4. who have different cultural understandings of the world
5. whose lives do not fit neatly into academic "schedules", etc.

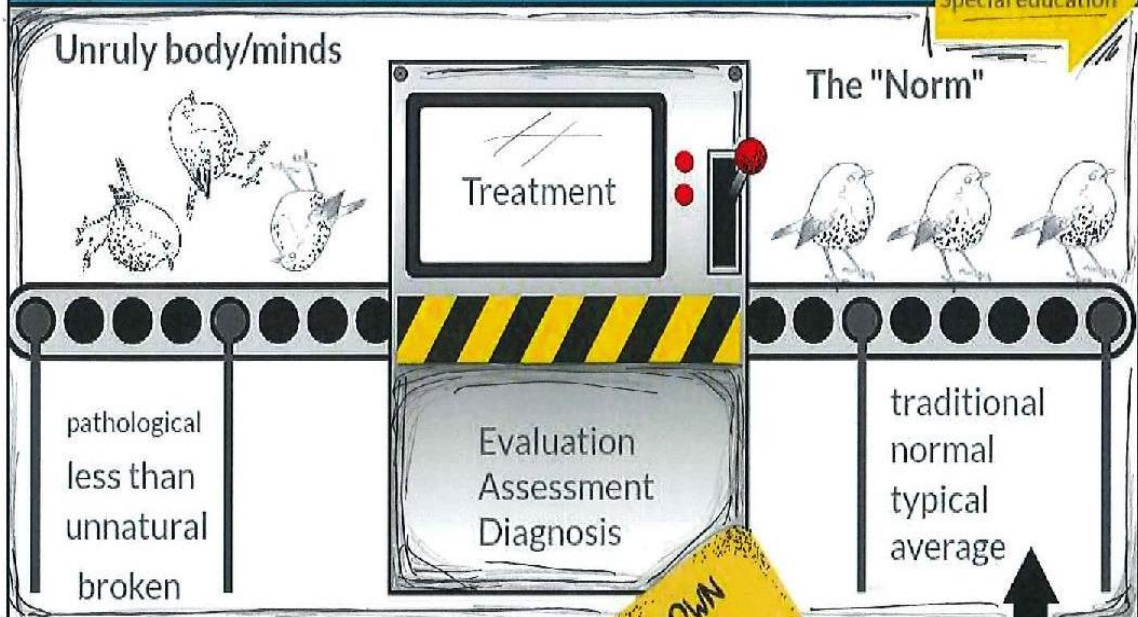


In response to unruly bodies,

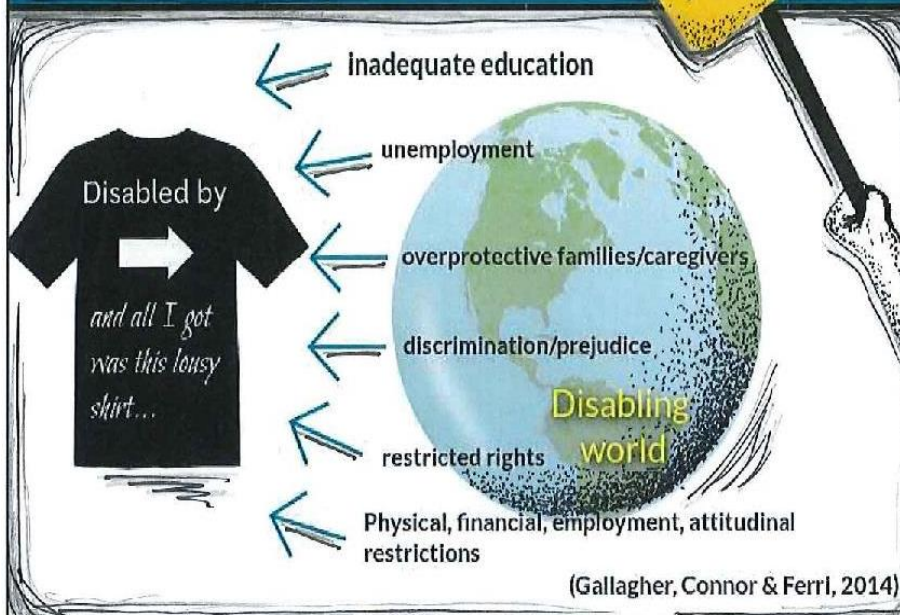
"Schools have developed elaborate practices that support the rigid organization of classroom space and time, the overriding emphasis on discipline, and the careful monitoring of the curriculum (Erevelles, 2000, p.33)

Medical Model vs Social Model of Disability

MEDICAL MODEL



SOCIAL MODEL



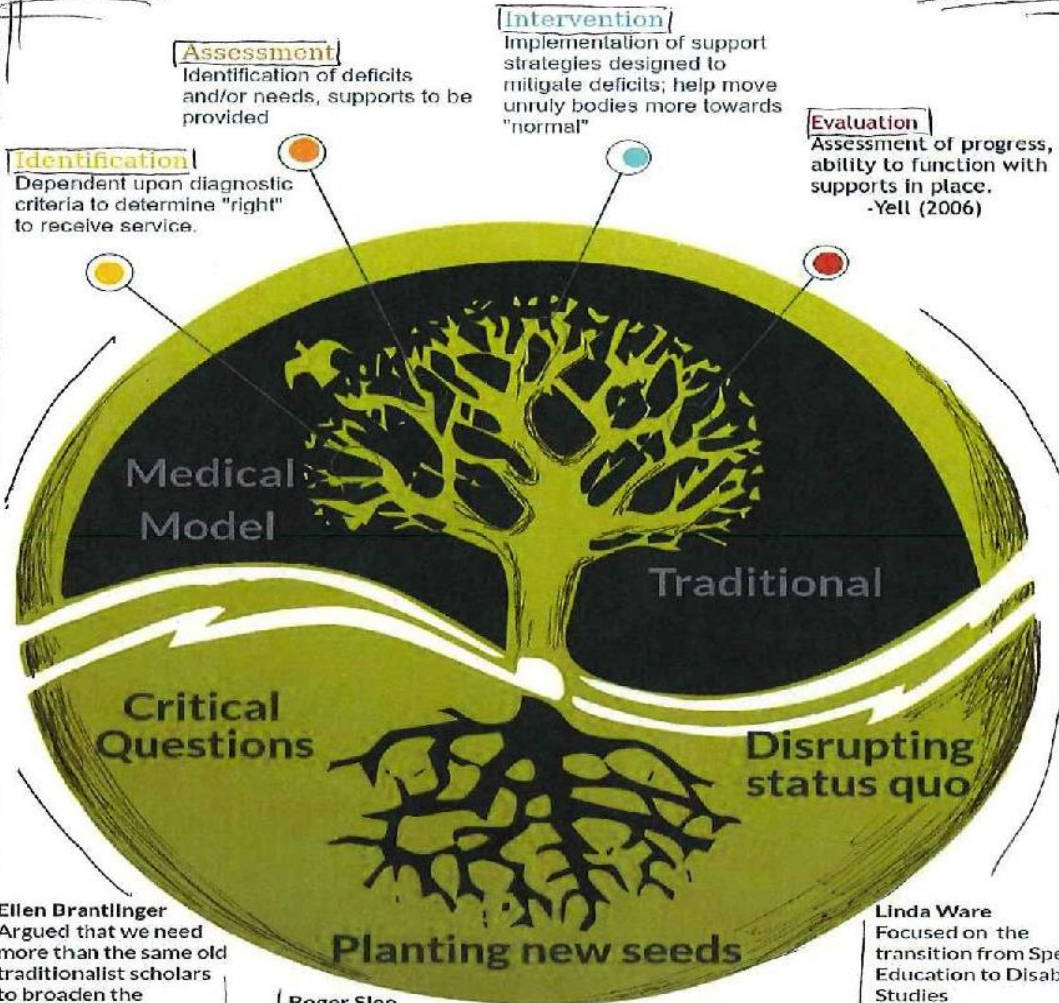
On Eugenics

Darwin describes people with intellectual disabilities as inferior to a "better class of men" and holds them responsible for "human descent," paving the way for eugenics. (Gelb, 2008, p.35).



SPECIAL EDUCATION

Special education has foundations in the medical model of disability



Ellen Brantlinger
Argued that we need more than the same old traditionalist scholars to broaden the literature



Roger Slee
Not in agreement with the practice of making "defective" kids fit the school



Burton Blatt
One of the original scholars to challenge the medical model.



Linda Ware
Focused on the transition from Special Education to Disability Studies



*Yes, but where all my scholars of color at?
Where all my scholars with ID?*

Education Timeline

This timeline chronicles important events/attitudes/policies and other happenings in the US that impacted the ways in which students with disabilities were or oftentimes were not allowed access to general education.



It is important to know the history of education for students with ID in the US, in order to understand the barriers that students experience when they enter higher education...

No presence in schools • Separate but (not) equal • Mainstreamed • Included and valued

1800-1860

- challenges to centuries old ideas of deviance, less than human
- charity focus to salve conscience of benefactors
- children were hidden away to avoid stigma
- beginning of the common school movement

Early Reform

1860-1950

- disability pathologized as a defect to be eliminated
- students with ID segregated so they would not negatively impact others
- tracking of "culturally deprived" students

Stagnation and Regression

THE

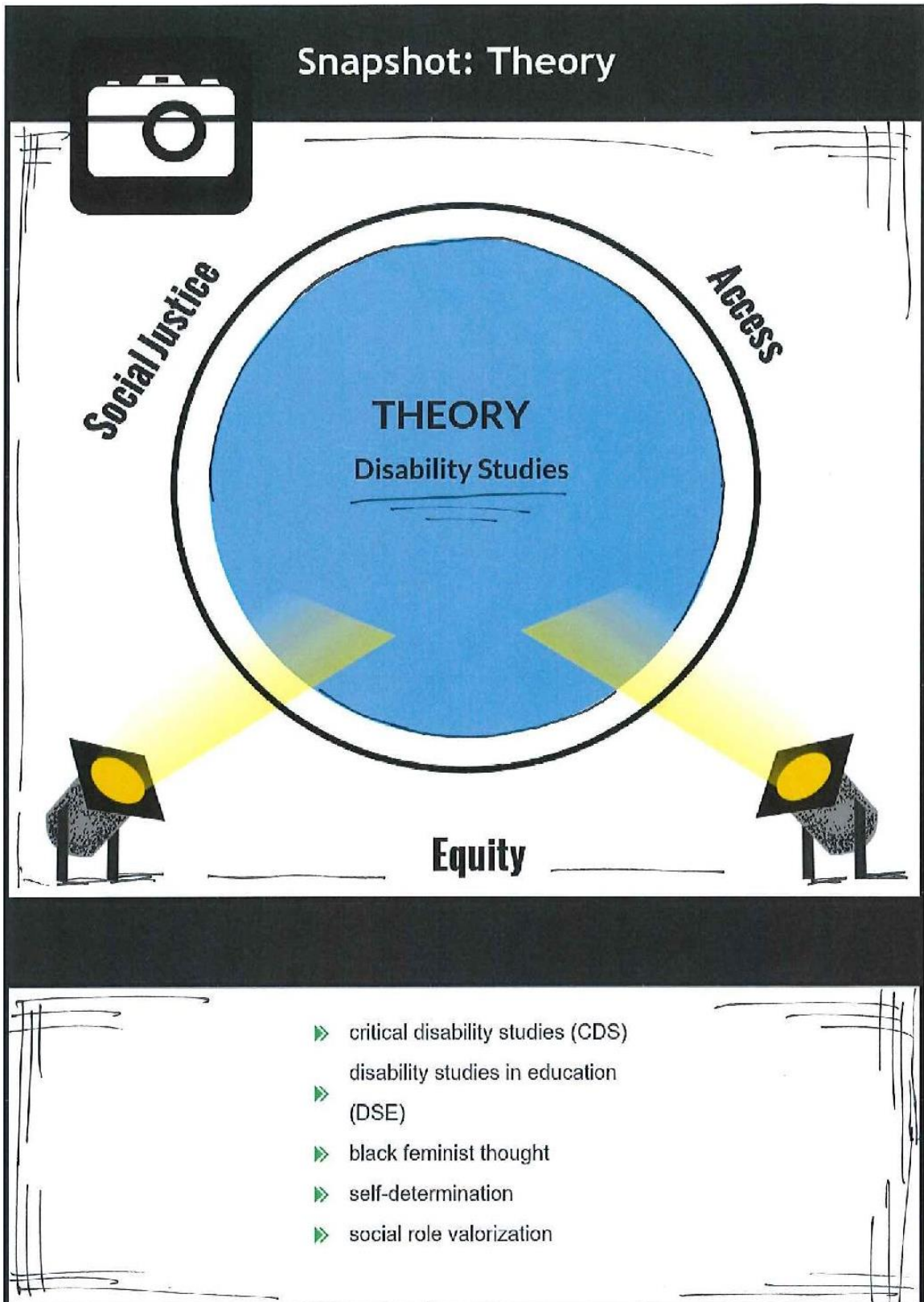
I
D
E
A
L

1950- present

- fights for civil rights began
- IDEA and FAPE were enacted
- Inclusion debate
- challenges to medical model

Contemporary Reform

Snapshot: Theory





Disability Studies

MULTIDISCIPLINARY
exploration of
disability as a social
construct

- that challenges the medical model
- that views disability in relation to "whole universe"
- that explores how study of disability can inform multiple disciplines
- that expands scholarship beyond the applied fields into the humanities and social sciences



**Disability
Studies in
Education
(DSE)**

Sparked in 1972

Union of the Physically Impaired
Against Segregation (UPIAS)

Fundamental principles

Disability is caused by social
conditions.
To eliminate it:

- no one aspect such as incomes, mobility or institutions can be treated in isolation,
- disabled people should, with the advice and help of others, assume control over their own lives, and
- professionals, experts and others who seek to help must support control by disabled people.

(UPIAS, 1972)



Photo courtesy of Steven Cozart

This research focuses on critically exploring the intersection between disability and education. Read on to see what other critical perspectives have influenced me as a scholar.

Critical Disability Studies (CDS) in Education

Critical Disability Studies

Challenges divisive labeling in special education and focuses on the need to adapt social and material environments to "ensure equity for folks with diverse abilities (Cory et al, 2010)



CAUTION!

Chris Bell (2010) Critique

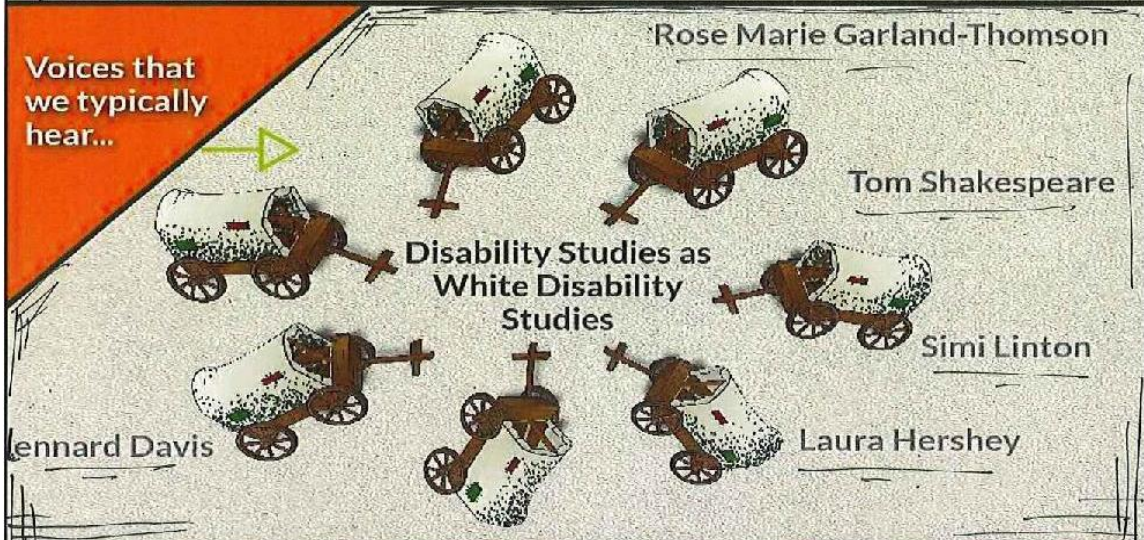


DS scholarship is dominated by white scholars, with and without physical disabilities.

Disability is seen as monolithic.

Limited representation by scholars of color, scholars with intellectual disabilities, scholars with other intersectional identity markers

Voices that we typically hear...



Perspective from Scholar with ID:

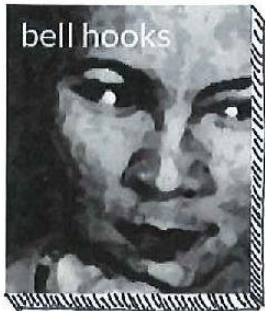
"I think it is good to be a disabled researcher. It's important because we are usually not given the opportunity to be involved, and some voices are heard more than others- but we all have disabilities."-Simon

Critical Perspectives

that inform this research

Black Feminist/Womanist Thought

(yes, I claim them both...)



bell hooks

Like Chris Bell's critique of Disability studies, black feminism and womanism disrupt the false universal that feminism represents a monolithic group



Alice Walker

Patricia Hill Collins (1996)
Gives us core elements of black feminism and womanism



Disruption



Emancipation



Agency



Resistance REVOLUTION



Collective



Interdependence



Critical Perspectives

that inform this research

Feminist Disability Theory/Studies (FDS)



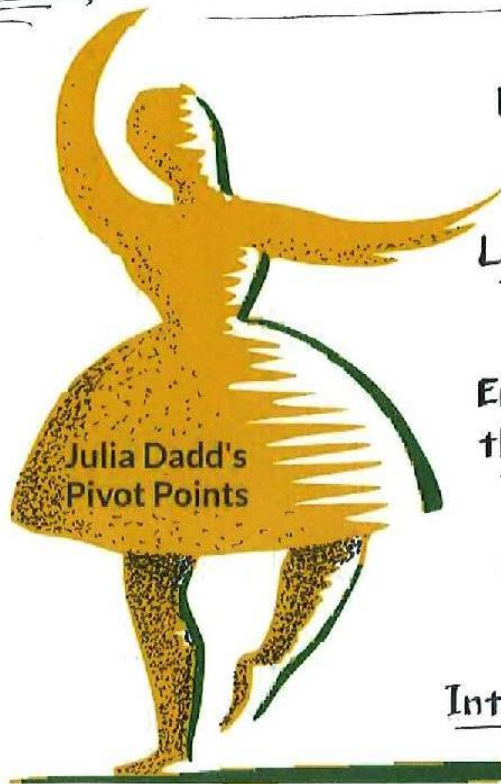
Dadds, 2011)



Acknowledgment of a "range of sexual identities/ways of being/physicalities/psychologies"

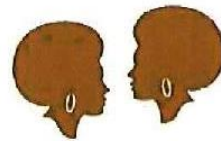
Women's rights to live "educated and economically" powerful life

Focus on injustices enacted upon female body



Julia Dadd's Pivot Points

Reflexivity



Lived experience



Engagement with the margins



Embodiment



Interdependence



Snapshot: Praxis



Social Justice

Access

PRAXIS

Critical pedagogy/
advocacy

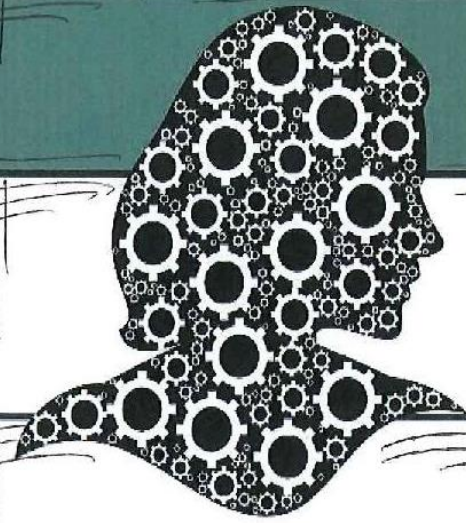
Equity

- ▶ inclusive pedagogy
- ▶ engaged pedagogy
- ▶ self-determination
- ▶ critical consciousness
- ▶ social role valorization

Pedagogy

Practice for the educator

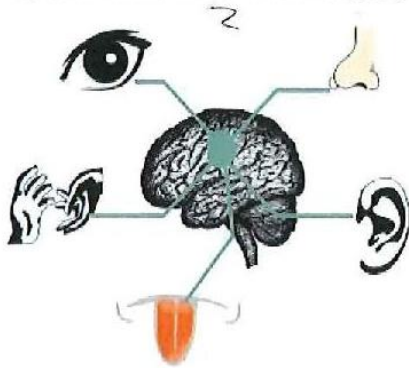
The art/practice of teaching



Inclusive Pedagogy

Informed by feminist disability studies pedagogy (fdsp) (Carter, 2015)

Multi-modal/multi-sensory



Different ways of knowing are valued and included

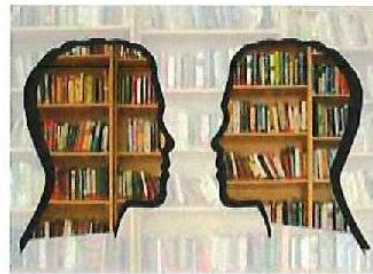
Access for all students

Social Justice

Engaged Pedagogy

from bell hooks (1990)

Shares many of the same characteristics as inclusive pedagogy, with a focus on engagement between student and teacher



Mutual engagement between student and teacher

Mindful of power differences

Requires flexibility, responsiveness, and reflexivity on part of teacher

I resonate with hooks argument that education should be a practice of freedom that requires teachers to be committed to a critical consciousness, like their students.

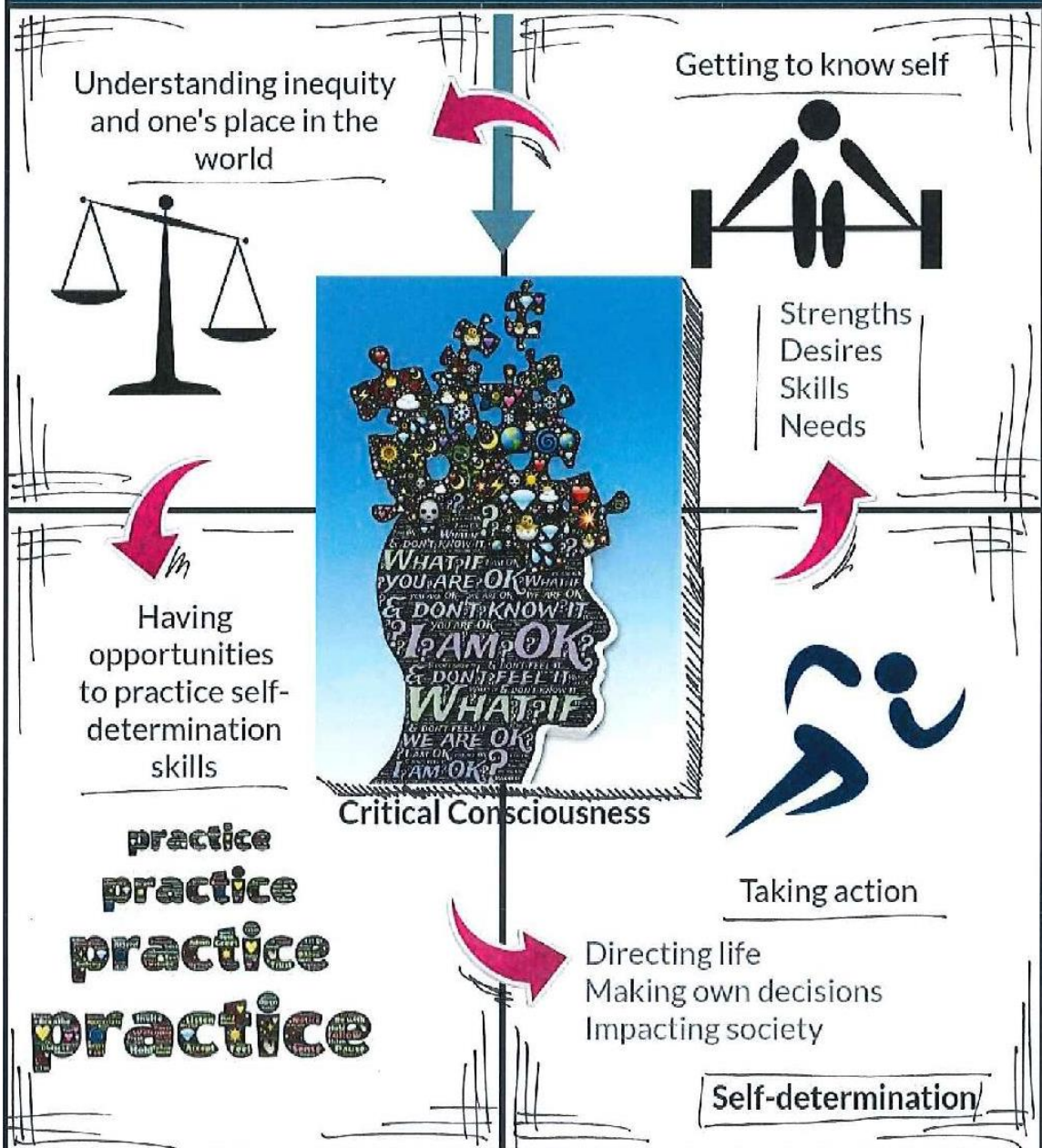


Critical Consciousness and Self-Determination

Practice for the Person

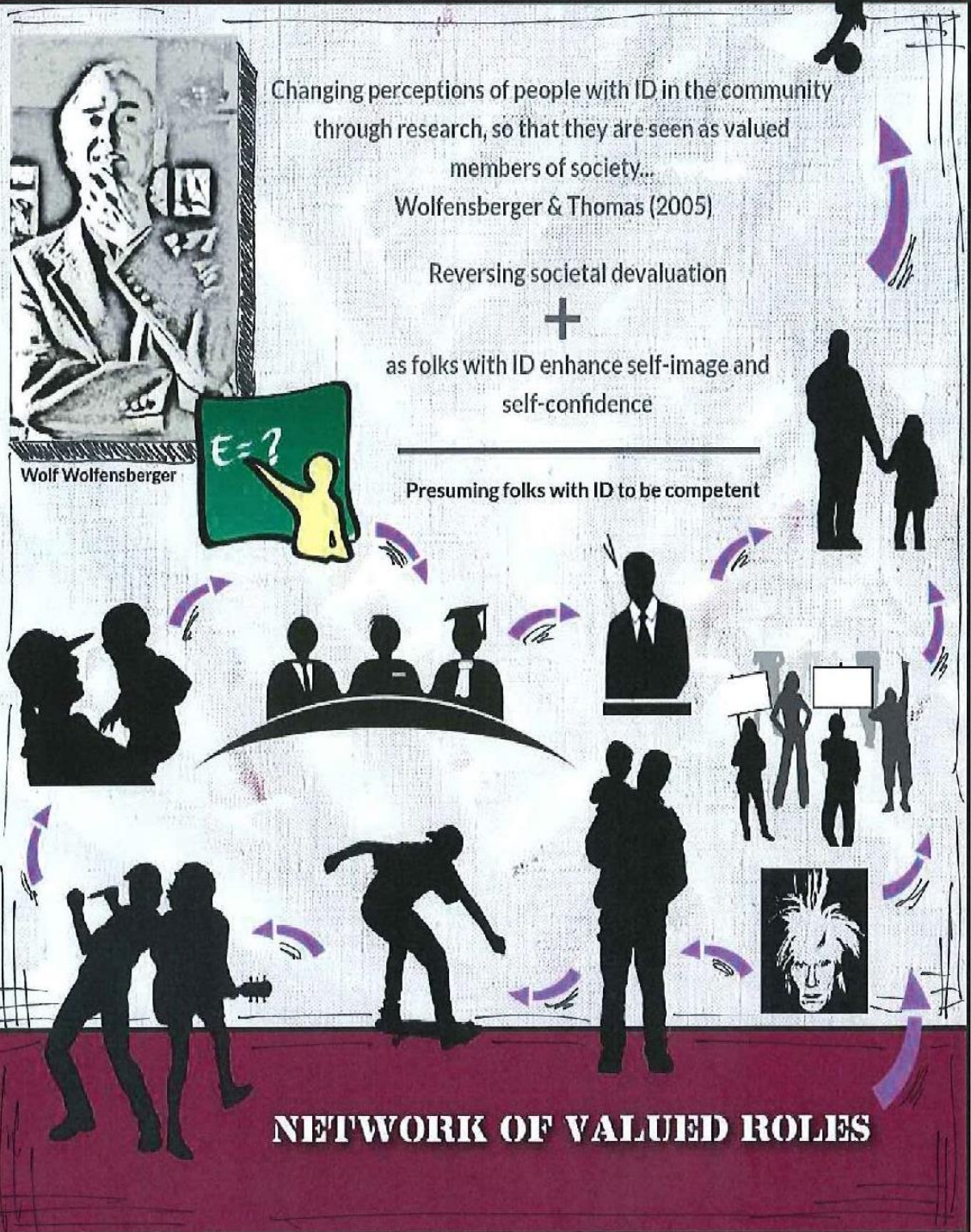


People exerting control over their lives by knowing themselves well enough to be able to identify realistic goals that reflect strengths and support needs (Ankeny & Lehman, 2011)

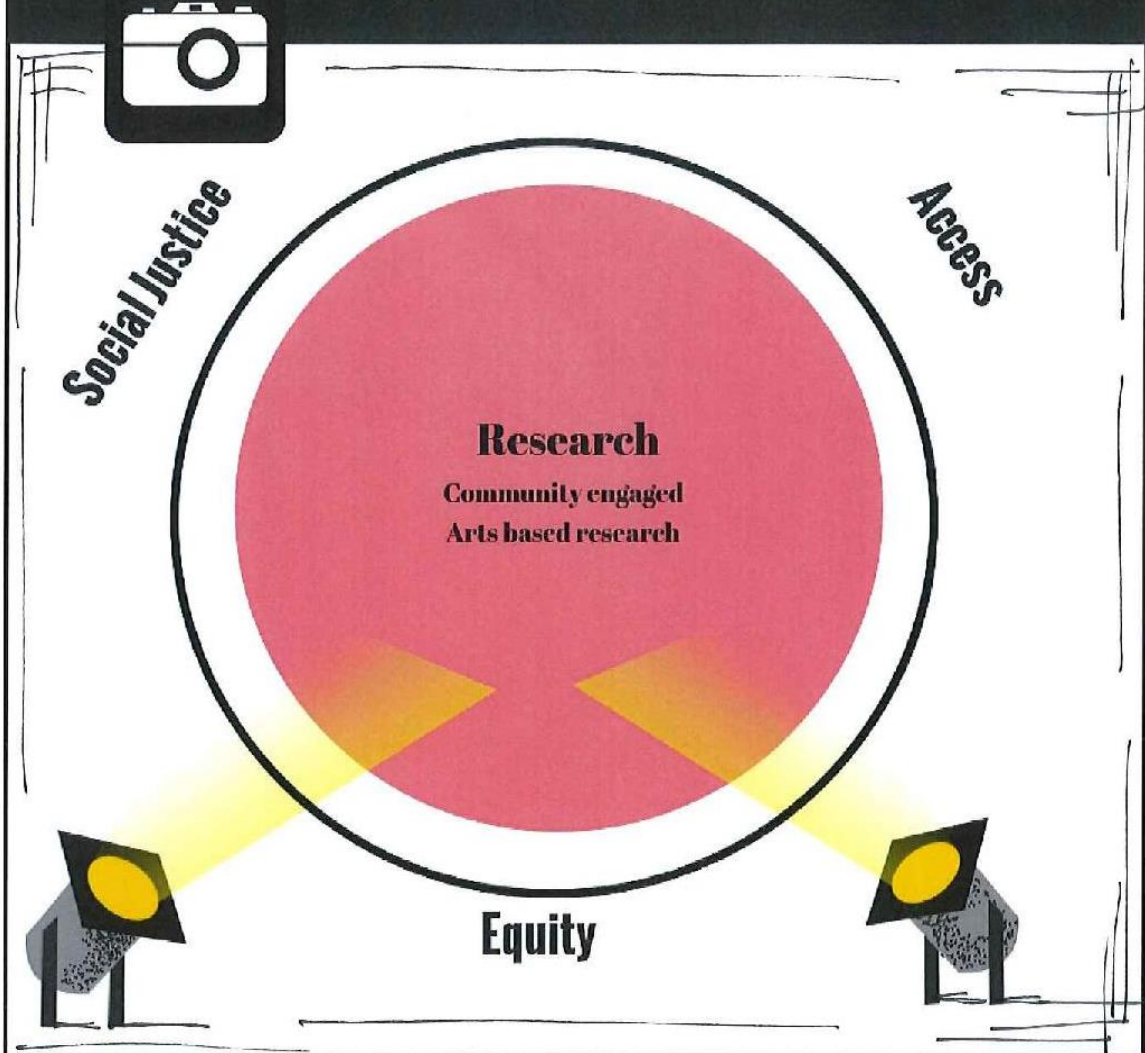


SOCIAL ROLE VALORIZATION

Practice for the community



Snapshot: Research



Community Engaged Research

Informed by:

- ▶ emancipatory/inclusive research
- ▶ feminist research
- ▶ arts-based research

Traditional Research Approaches

Traditional approaches to disability research in the US operate with the understanding that disability is due to "individual pathology."



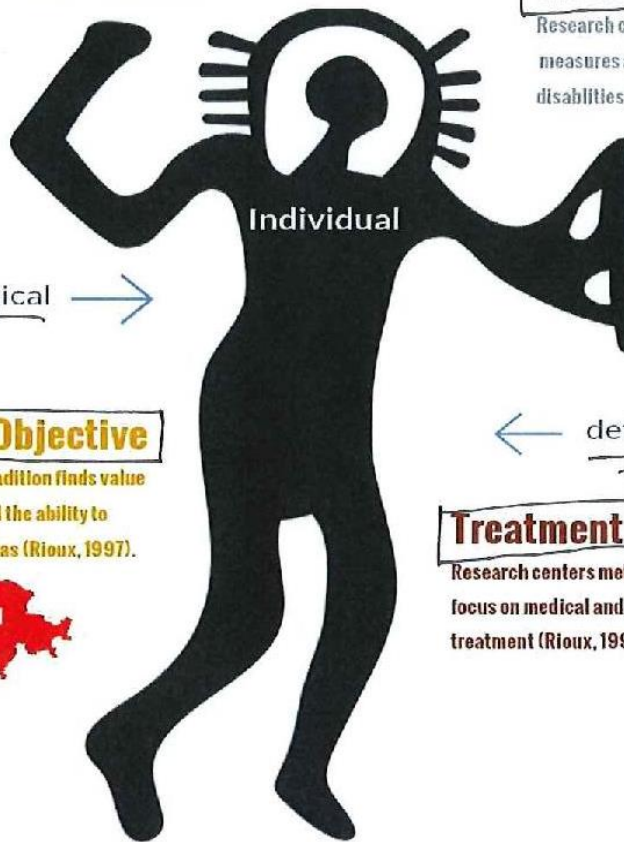
"Germ theory"

Research guided by understanding that disability is caused by a mental or physical condition that can be treated through medical intervention (Rioux, 1997).



Measurement

Research centers inquiry that measures and assesses people with disabilities for "deficits" (Rioux, 1997).



Neutral/Objective

Research in this tradition finds value in "objectivity" and the ability to remain free from bias (Rioux, 1997).



Treatment

Research centers methodologies that focus on medical and/or rehabilitative treatment (Rioux, 1997).



"The scene facing every physically impaired person, then, is of an army of "experts" sitting on panels which are set up all over the country. These "experts," armed with the latest definitions and tests for measuring, will prod and probe into the intimate details of our lives. They will bear down on us with batteries of questions, and wielding their tape measures will attempt to tie down the last remaining vestige of our privacy and dignity as human beings" (UPIAS, p. 17)



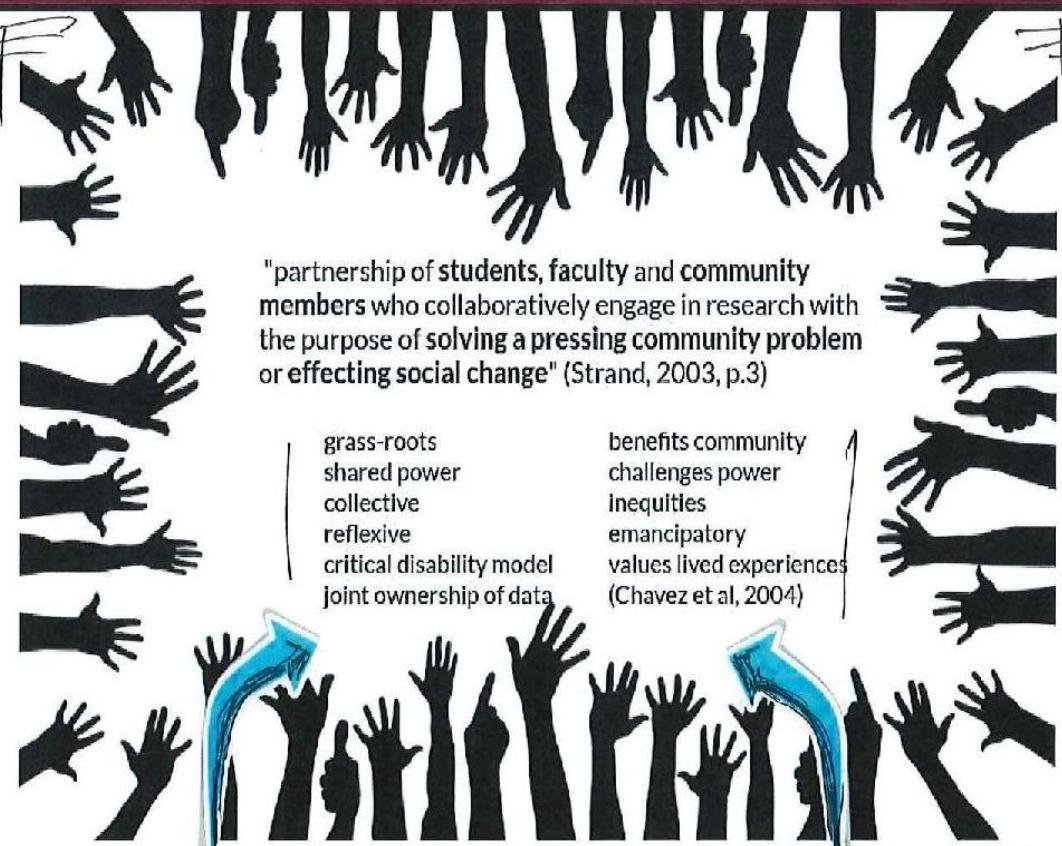
Emancipatory Research

informed by "disability methodology"

Emancipatory research challenges the medical model, and "illustrates the complexity of disablement" (Stevenson, 2010, p.40)



Community Engaged Research

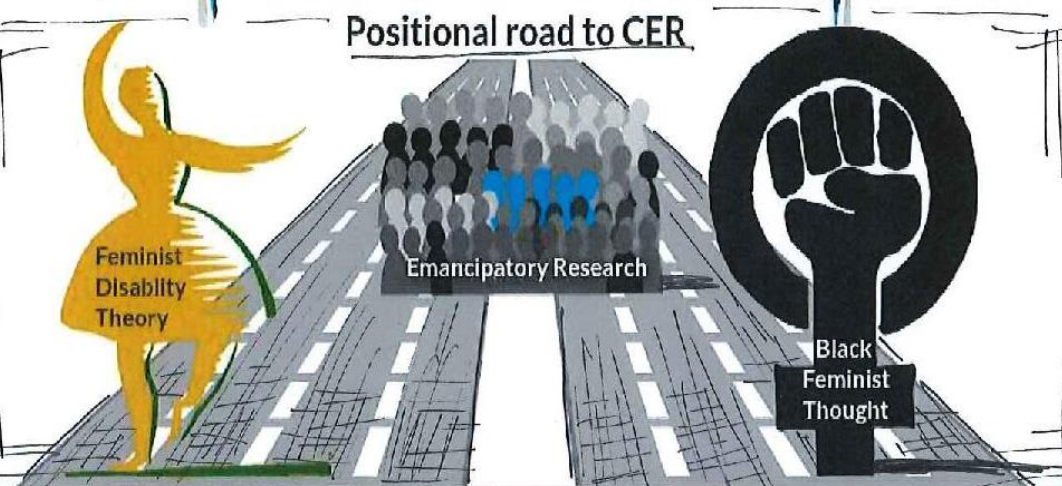


"partnership of students, faculty and community members who collaboratively engage in research with the purpose of solving a pressing community problem or effecting social change" (Strand, 2003, p.3)

grass-roots
shared power
collective
reflexive
critical disability model
joint ownership of data

benefits community
challenges power
inequities
emancipatory
values lived experiences
(Chavez et al, 2004)

Positional road to CER



Principles of black feminist thought, emancipatory research and feminist disability theory paved the way for the use of CER

Arts-Based Research



Engaging the whole "thinking-feeling person" (Alexander, 2003)



Broadening qualitative methods that seek to "describe and understand meaning" rather than explain, predict or control behavior (Alexander, 2003, p.3)

Arts-based research-
because my brain works
that way...

Encouraging emotional connections
that can lead to social change
(Alexander, 2003)

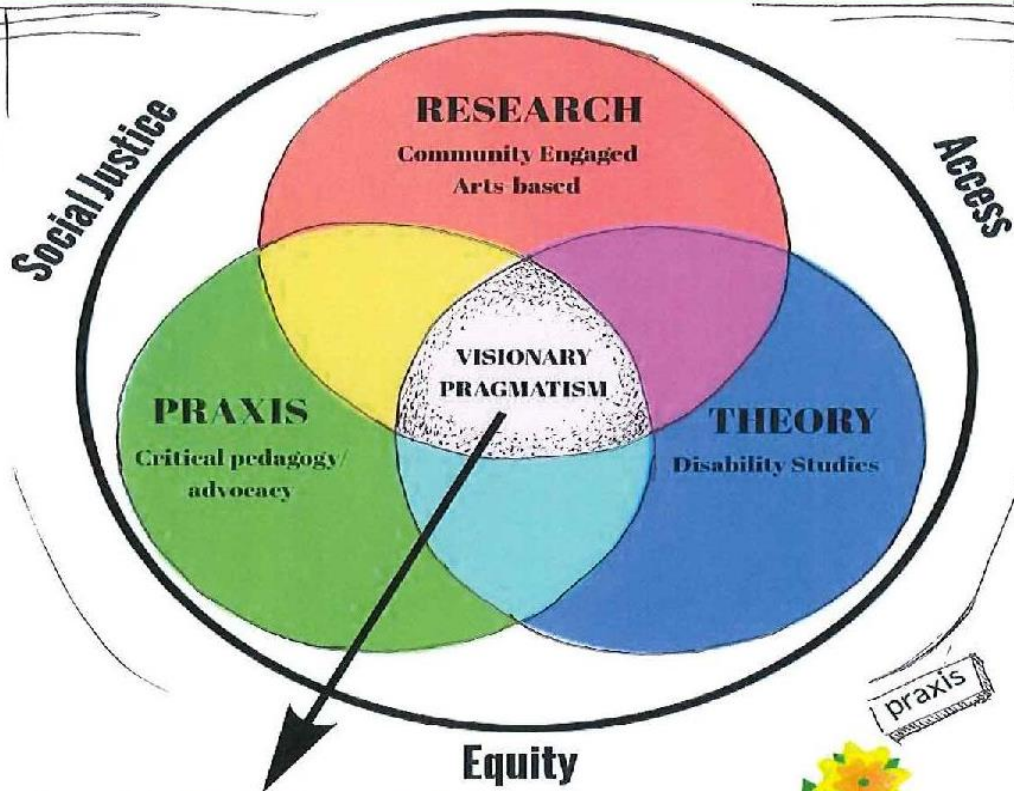


Poetic Inquiry

Using poetry
to describe life as it is
presenting the essence
of an idea
shaping the uniqueness
of voices and minds
stretching the bounds
of scholarship
providing access
to those who have been
unseen
unheard
not valued
for the richness
of thought
they are capable
of bringing
to the surface
for all to share

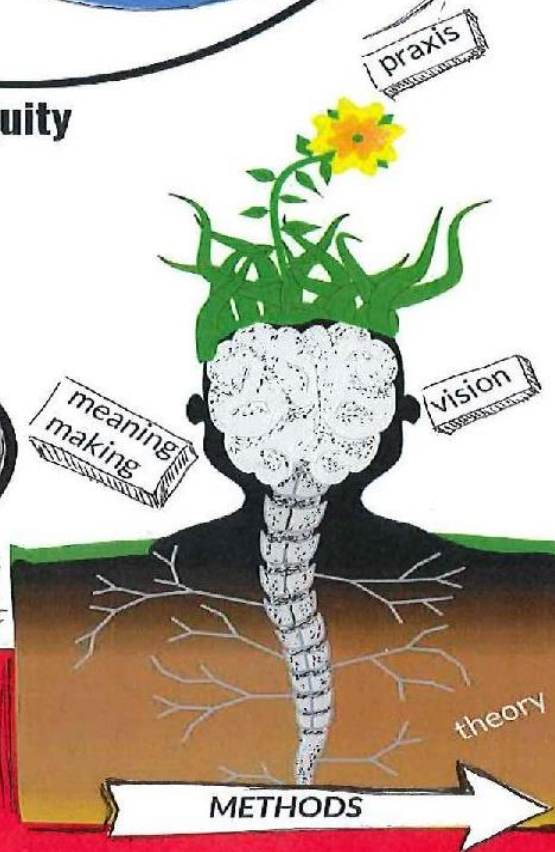


Visionary Pragmatism



Theoretical vision that is connected to "informed, practical struggle;" "linking visionary thinking with pragmatic action" (Collins, 1996, p.188).

Envisioning PSE programs this way calls for theoretically connected research that pushes beyond programming - more about that in the conclusion...



Remember these concepts as you read the methods, analysis and conclusion chapters- you will see all of these ideas again!!

CHAPTER V
METHODOLOGY

Notes from a Researcher's Journal Methods at a glance

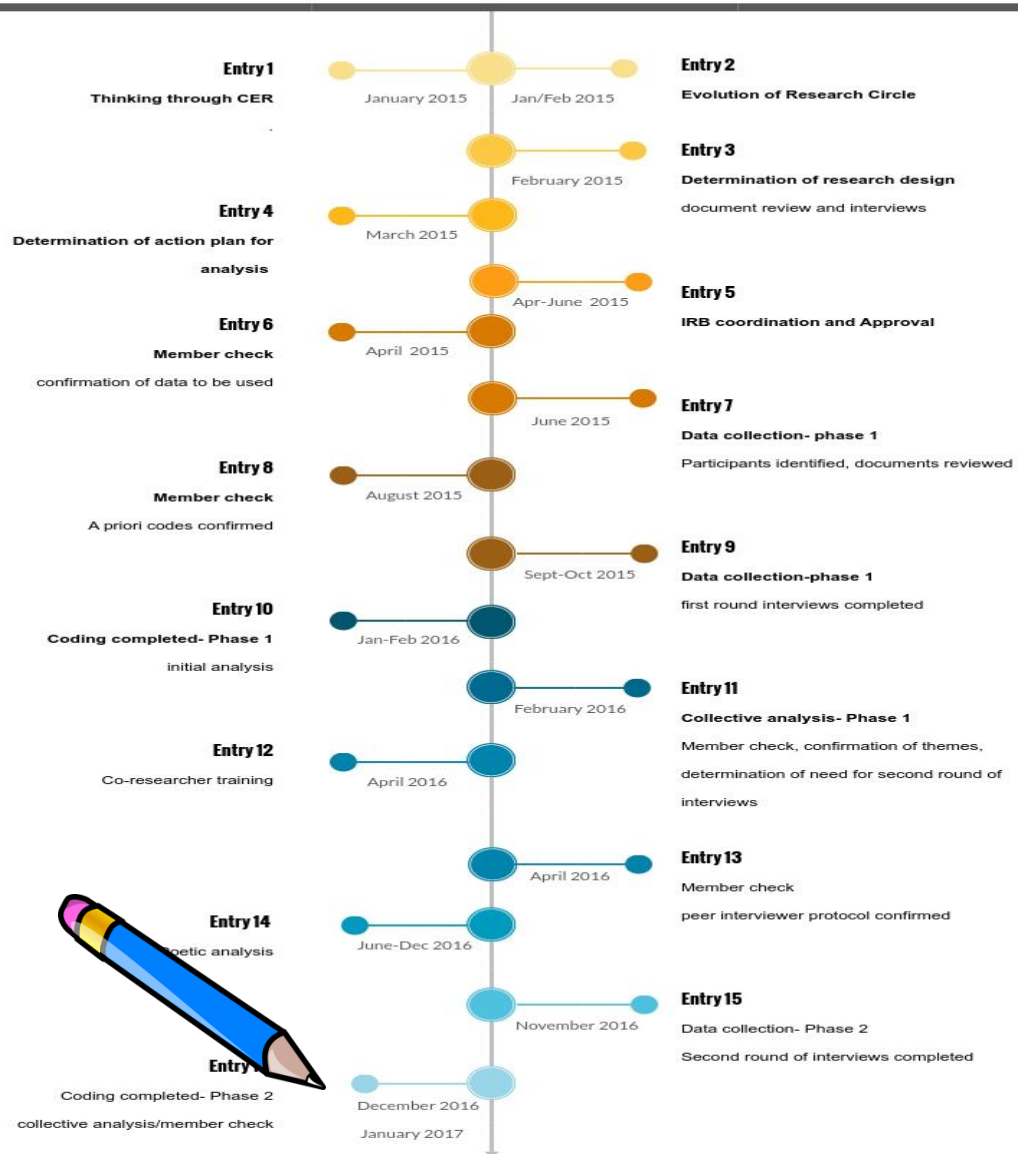


Figure 9. Methods at a Glance

However, probably with the best of intentions people who have done inclusive research have not always explained what they do, and how they do it, when working inclusively. This led to a mystification of the process. The myth can develop that somehow people magically get it right, but how the magic works is obscure. The hard work, the finely honed skills, the self-restraint researchers need to exercise have been camouflaged, as are the particular contributions made by people with learning difficulties (Walmsley, 2004, p. 69).



Journal Entry 1 (January 2015):

Thinking through CER- As a part of my coursework through the Cultural Foundations program at UNCG, I determined that Community Engaged Research (CER) could be a viable strategy for participatory research, evaluation and planning with the non-profit that partners with the program of study of which I am Director (Integrative Community Studies). My introduction to community engaged research felt like a coming home. The emphasis on the collective, the valuing of multiple perspectives, the sharing of power, all very exciting concepts that align so well with my own position as well as the philosophy of the organization for whom I work, inspiring me to write the following:

At the intersection of critical questions
about whose knowledge is worthy
about who gets to sit at the pedagogical table
about how we value ways of knowing from bodies that are not
“claimed, positioned or represented within
the hegemonic ideology of the community at large” (Siebers, 2008)

there is an opportunity
an opportunity to come together and engage with one another
to break bread and pass the feather
to make space for the untangling of those limits
that have been imposed on self-direction
by acts of domination (Steinberg, 2012)
and “educational alienation of the individual” (Kincheloe, 2007)
At this intersection that challenges
the (dissing) of ability
we have a responsibility to presume competence
to “awaken the political consciousness” (Hudak, 2013)
of ALL of us sitting at the table
and as we critically examine our own complicity
in perpetuating ableist assumptions of sovereignty
based on sometimes arbitrary notions of
who “can”
we may ask, like Nikki Giovanni (2003)
“how can anyone be responsible without power...
power implies choice”
and if choice implies voice
then this intersection of the collective
becomes doubly significant
where this sharing of power and “knowing ways”
provides a foundation for the centering of
perspectives that have been (dis)counted
the creation of a space for claiming the right to produce knowledge
It is this intersection that I choose to occupy
in my own journey to educational conscientization
Sankofa spirited in my location of privilege

hoping to help open doors to a sense of community action
as ally
student
activist
facilitator
co-producer of knowledge
and most importantly
lover of learning
and the growth that comes
from acknowledging one's own
unfinishedness in the face of
the bounty of life knowledge sharing space at this table

In addition to the principles of CER that match so beautifully with our goals, like feminist researchers, it is essential to consider reflexivity and reciprocity in our research process. Reflexivity asks us “what can we know and how do we know it” (Hesse-biber & Piatelli, p. 495). In doing so, it challenges positivist paradigms that value “objectivity, detachment, neutrality and universality” challenging racist, gendered, ableist ideas that set up a divide between researchers and the researched (Hesse-Biber & Pitelli, 2012).

It requires me as lead researcher to understand how “the world is mediated by the self” and that “what can be known can only be known through oneself, one's lived experiences, and one's biography” (p. 496). I have to examine my own history and lens through which I see the world, and be transparent about that with my fellow researchers. This is important because a

reflexive approach “fosters sharing, engaged relationships and participator knowledge building practices” which will ideally produce “less hierarchical and more ethical, socially relevant research” (p.496). The use of poetry is one tool that I use to hold myself accountable to challenging

my long held
beliefs
understandings
assumptions
about Truth
with a capital T
draped around me
like an old tapestry quilt
dusty and dated
ready for a new hand
fresh needlework
excising old threads
exposing
what has been hidden
behind all of my
carefully constructed
stitching
around power

looking for the skill
of a deft hand
to change “consciousness,
encourage collective empowerment,

and transform both researcher and participants
in the research process”(Hesse-Biber & Piatelli, 2012, p.508)

A reflexive approach challenges the power of the empiricist paradigm by attempting to “deconstruct power relations between the researcher and participants by decentering the authority of the researcher’s voice. (Hesse-Biber & Piatelli, 2012, p. 507).

The act of decentering authority also requires an understanding of reciprocity defined as “authority and responsibility for knowledge creation are shared” (Dostilio, et al, 2012, p.18). This challenges a more traditional approach to university/community research where the university decides that is going to do research “for” a community, requiring a move towards the engagement of community partners so that they have more choice in their level of involvement and in the “creation and critique of the knowledge created” in the research process (p.43). This level of reciprocity moves beyond “mutuality” and one-dimensional focus on mutual benefits of each individual member, to a more holistic, dynamic process of knowledge production that considers how the collective can benefit together. These are key elements that I have to consider as I look to bring our research circle together.



Journal Entry 2 (February, 2015):

Evolution of research circle: After confirming this intention with the leadership of the non-profit, Beyond Academics, on Feb 20th 2015, I convened

the *existing* quality improvement committee and I explained that the organization had made the decision to use a participatory, community engaged research process to support student involvement in continued shaping of outcomes for the program. I shared my position, provided an overview of the CER process, confirmed agreement to participate, and then encouraged discussion about how this group will choose to operate within this framework.. Members of the quality committee turned community research circle include:

- Lead Researcher- ICS program director
- Students- 4 Students enrolled in the ICS certificate and 1 social work grad student at UNCG
- Administrators- Assistant Executive Director and staff of Beyond Academics
- Community Residents- Representative from non-profit, InFocus , and from Think College
- 2 Faculty from UNCG

Note about co-researchers: Although my role situates me as “lead” for right now, I consider all of our community members to be co-researchers, as we have collectively designed and executed this study. I think that it is important to further identify *student* co-researchers as such, to highlight the fact that as the target stakeholders, they were also actively involved in the research process. I apply this term to the 4 students from the program who were involved in the community research circle. This becomes a bit more complicated, because these four students were also research participants. We decided collectively that this was important- to ensure that students in the program were involved in all levels of

research, which is an integral part of community engaged, emancipatory research.

As we renewed the purpose and function of this group as a research circle, we followed Strand's (2003) guidelines for entering and conducting community partnerships: being clear about worldview, collective feedback on goals and strategies for the community group and important boundaries regarding trust and mutual respect.

- Worldview- the members of this existing group had already come together with a common purpose, which is to support students with intellectual disabilities in college.
- Goals and strategies- the group had traditionally been given goals as determined by the board and administration of the non-profit- in the CER process, they were asked to help identify goals and strategies as a group, and then take action to follow through on them.
- Trust and mutual respect- Respect for the students in this program is a crucial element of supports- that same respect, and trust was mutually agreed upon by all members of the research circle.

The initial meeting also involved discussion about role clarification, where we identified "areas of expertise" and established "guidelines for the team process" that help to "mediate power and control issues" (Ward & Trigler, 2001, 58). I was transparent about my role as director and as a doctoral student with the intention of executing research for the purpose of my dissertation, but also for the purpose of becoming a jumping off point for future CER and program development. There was collective agreement to this, and confirmation that I would take on the responsibilities of coordinating circle meetings and facilitating and writing up the

analysis for this stage of the research. The group determined that the next meeting would be used to identify research design.



Journal entry 3 (February, 2015):

Determination of Research Design: During the meeting on 2/20/2015, we discussed significant theoretical viewpoints upon which we all agreed, like the participatory component of research, self-determination/self-direction and access to higher education as a social justice issue; elements which all confirmed the linkage that I was making to critical disability studies and disability studies in education. This discussion led to a collective decision on the following questions and design:

Research Questions:

- 1) What do students with ID consider personal growth (as it relates to being in college)?
- 2) How do students perceive supports needed to achieve their desired goals?

Research Design:

During the initial quality improvement committee, there was collective agreement to move forward with a research design that was built on respect, would place more control in the hands of students, would prioritize the goals of students with ID, would lead to practical outcomes for students and for the program, was based in a more critical model of disability that challenged

assumptions of the medical model and centered the experiences of students with ID (Stevenson, 2010). Community engaged research was a logical choice and the research circle was confirmed. There was further discussion about the need for a reflexive process that allowed for continual member checking and transparency about positions of circle members, as well as strategies for ensuring that student participants were able to evaluate and provide feedback about the research process, in accordance with principles of emancipatory, community engaged research (Hammell, 2007).

Data Collection:

The research circle decided that document review and interviews of students enrolled in the PSE program would be the most effective ways to collect data. It was determined that 12 participants would be an ideal number, with 3 students representing each year/cohort. The following data were identified by the circle:

- 1) Student documents (applications, intake assessments, Person Centered plans, senior portfolios, other relevant documents from student academic records)
- 2) Transcripts of interviews using Personal Outcome Measures tool (POMS). This tool is currently being used annually by Beyond Academics to remain in compliance with its national accrediting body, the Council on Quality Leadership (CQL). It has been in use for 20 years by this monitoring body, and has been deemed a reliable and valid tool for measuring quality of life outcomes (CQL, 2016). Transcripts of interviews

that have already been completed will be incorporated into document review. For those students who still require interviews, the same set of standard questions that have been used in the POMS process will be used, and will be submitted to the IRB as the interview protocol for this study.

3) Notes from community meetings- I shared with the circle that poetry is an important part of my academic lens, and that I would like to use poetry as a form of analysis for these meetings, as well as with student generated data. Members were very receptive to the idea of this form of analysis. I explained that I will bring examples of it to the group as we move more deeply into that part of the research.

Once this data collection approach was identified, discussion of the plan for data analysis was scheduled for the next research circle meeting.



Journal Entry 4 (March 2015):

Determination of action plan for analysis: On 3/23/2015, the circle reviewed a concept map (see appendix A) that I provided for the overall project, as well as a proposed timeline for data collection and subsequent evaluation and provided feedback that has been incorporated into the documents. Each member who was present identified the action steps that they were willing to take regarding the collection of data and evaluation, and I agreed to follow up with members in absentia. I also informed the group that although I felt it was my responsibility to be very involved in data collection, transcription, coding and analysis that I could I also offer sessions on how to code, etc. for any member

who would like to be involved but may need more information to feel comfortable in the co-researcher role. Members agreed to assist with research design, to assist with coding, to assist with the IRB application, to assist with thematic analysis, and to assist with reporting as opportunities arose.

Thematic analysis was determined to be the analytical method that was most appropriate to data being collected through interview and expository documents related to personal goals, reflecting what Rosenberg & Yates (2007) define as methodological rigour in analysis. The research circle was in agreement that preliminary codes and categories would be initially organized by me, and they determined that given the amount of documentation available for review, and the capacity of the research circle for analysis, that 12 participants was logistically an ideal size for this phase of research.



Journal Entry 5 (April-June, 2015) :

IRB Coordination and Approval: From the date of 4/1/2015, with guidance from faculty circle member, I began the IRB application process and developed recruitment scripts, consent scripts and the interview protocol to be approved by the IRB office. I also confirmed that faculty members would be identified as co-investigators, and that all other members of the research circle would be identified as research assistants. The inclusion of student stakeholders in the research process was unique for the IRB office, however there was an openness to the participatory nature of this study, and students were permitted to

be listed as research assistants, which did not require full human subjects research training. The application was submitted on 5/28/15. After responding to stipulations, it was approved on June 16th, 2015.



Journal Entry 6 (April 2015):

Member Check: On June 10th, 2015, I met with two student circle members, to talk about documents that we were likely to use- both agreed that the documents that I had identified to that point were relevant and meaningful:

- Applications/Intake assessment- applications used by both the ICS program and non-profit partner, Beyond Academics (BA)
- Success plans from First year seminar (FFL)- goal setting assignment required by FFL
- College support plans/ Person centered plans that include goals specific to use of program supports
- PATH and CIRCLES plans- plans that are developed each spring during person centered planning course
- Senior Portfolio- capstone presentation that contains overview of growth during college, and action steps for life afterwards
- Personal Outcome Measures (POMS) interviews- explained earlier
- College experience presentations- any presentations that relate to student's experience in college

These documents were gathered for all 12 student participants, de-identified, and then organized for coding.

During the same meeting, I explained the data analysis process to both student researchers. We did a sample coding exercise together, so that they

could make an informed decision about where they would like to be involved in the analysis process. One student seemed to have a great instinct for coding, and expressed an interest in being involved at that level. The second student was more interested in being involved once the initial coding was done, and when it was time to start identifying themes.



Journal Entry 7 (June, 2015)

Data Collection (Phase 1): On June 16th, 2015 I met with faculty co-researchers to discuss our plan for analysis and coding. We did a preliminary review of the data and determined our frames of analysis (Hatch, 2002, p. 163) through a line by line reading. Each frame consisted of essentially one to two concrete responses related to personal growth in college per line. As we reviewed, we “noticed relevant phenomena” or identified preliminary codes (Coffey & Atkinson, 1996, p. 29). The following set of a priori codes were determined.

- desired occupation
- location
- transportation
- independent living skills
- finance
- social involvement
- community involvement
- advocacy
- healthy living

There was mutual agreement that participant selection would be determined by identifying those with the most documentation available, and then using maximum variation sampling to ensure the broadest array of students with diverse ages, gender, race and disabilities. After this meeting, I was tasked with the responsibility of coding all documents, testing the efficacy of the a priori set, and identifying codes beyond. Initially, it was agreed upon that each case would also be coded by 3 other members of the circle, as a method for increasing rigor by developing continuity across coders. This became too difficult logistically however, and the final coding plan involved two coders per case. Coders included the following:

- Lead Researcher
- Circle member and faculty co-researcher
- Circle member and student co-researcher
- Circle member and intern co-researcher



Journal Entry 8 (August, 2015)

Member Check: I met individually with Dolphin and with Genevieve on August 26th, 2015 to overview the coding process. Preliminary coding attempts verified agreement with a priori codes, and both students coded independently after this meeting, with the exception of a few clarifying questions as they completed their coding.



Journal Entry 9 (September-October, 2015)

Data Collection (Phase 1): During the month of September 2016, I completed POMS interviews with the 6 students who did not have a 2016 interview on file. These interviews were completed and transcribed in preparation for coding.



Journal Entry 10 (January-February, 2016)

Coding (Phase 1): As documents were completed and coded, data was added to a coding notebook that was created and organized by year and by case so that codes could be compared across different axes. I compared coding by all coders and through thematic analysis (Hatch, 2002; Attride-Stirling, 2001). I used the following steps to determine a preliminary set of potential categories and themes to be reviewed by the research circle: 1) coding of raw data, 2) identification of coding categories, 3) construction of proposed themes, 4) discussion and exploration of themes by circle, 5) summarizing of themes, 6) interpretation of patterns (Attride-Stirling, 2007).



Journal Entry 11 (February, 2016)

Collective Analysis (Phase 1): During our research circle meeting on Feb. 23rd 2016, we reviewed the codebook and discussed the list of potential categories and themes that I brought to the circle (see table 3). The following potential themes were introduced for member checking purposes:

- College as tool for developing Interdependence (supports/relationships/sense of belongings)
- College as a vehicle for “critical consciousness” (consisting of cognitive awakening and movement to action – rights/meaningful roles/campus and comm. Involvement)
- College as path for self-determination/way to take control of your life
- College as path to career and financial independence (*consideration that there are separate meanings between career & finance*)
- Participation in college as social justice issue

The research circle was generally in agreement with categories and codes, offering minor suggestions about categories that could be collapsed. More significant feedback came with the observations that 1) the data did not speak to the second research question, 2) codes were present regarding external motivators for college, but not categorized as such, and 3) initial coding did not capture “barriers” to personal growth.

Table 3. Coding- Main Codes to Categories (cont.)

Main codes	Subcodes	Categories
Participation in campus and community activities	<ul style="list-style-type: none"> part in variety of campus activities part in variety of community activities volunteering using community resources using campus resources community service mentoring exploring new places in the community participation in social activities expanding community involvement involvement in faith community 	<p>Campus and community</p>
Support needs	<ul style="list-style-type: none"> support initiating friendships natural supports family supports parental support academic supports support for visual learners support for kinesthetic learners accommodations counseling support with meeting new people support with ind.t living skills support with relationship development support with college adjustment support breaking down information support with building confidence support with experiential learning support with assistive technology support with understanding limitations strategies for reducing anxiety support with cooking support with drivers testing support with maintaining natural supports support with faculty support with roommates emotional support support with health social support employment support support with self-care 	
Finances	<ul style="list-style-type: none"> finance management budgeting tracking spending making more income having paid work having enough money for life financial independence 	

Table 3. Coding- Main Codes to Categories (cont.)

Main codes	Subcodes	Categories
Self-exploration and improvement	<ul style="list-style-type: none"> • learning new things • self-exploration • improving communication skills • increasing self confidence • gain experiences/knowledge • exposure to new things • improving conflict man. skills • practicing skills • increase coping strategies • improve time management • cultural exploration • learning how to get around • improve organization skills • leadership opportunities • academic growth • wants to be challenged • getting degree • life goals • grades 	<p>Self-improvement/growth</p>
Membership	<ul style="list-style-type: none"> • education as family tradition • student identity • success as student • membership in campus groups • membership in faith communities • membership in community groups • living on campus • living in the community • traditional college residence life • being with people • membership with like minded people • part in campus activities • feeling accepted • inclusive classrooms • supporting faculty • meeting likeminded people • multiple social roles • service roles • real life learning • leadership opportunities • valued member of community • presence in community • feeling like an outsider • living with peers • student housing 	<p>Inclusion/having valued roles in the community</p>
College life	<ul style="list-style-type: none"> • live a new life • live college life • have college experience • graduate • real college life • get degree 	<p>Living the college life</p>

Table 3. Coding- Main Codes to Categories (cont.)

Main codes	Subcodes	Categories
Decision-making	<ul style="list-style-type: none"> • have a family • car ownership • home ownership • business ownership • live in location of choice • get married • have a good future • get driver's license • full life schedule • use of routines • religious self direction • personal responsibility • decision making • problem solving • pet ownership • agency • own guardian • personal planning • medical management • have own place • goal achievement • attend further schooling • medical management • personal interests • staffing preferences • recreational preferences • faith in self • scheduling preferences • belief in self • capabilities • having dreams • perseverance • commitment to succeed • self control • self-expression • positive attitude • satisfaction with areas of life being authentic self 	<p style="text-align: center;">Self-direction/self-determination</p>

Questions were asked about the necessity of having another round of interviews as 6 month update, and whether we would be able to include websites to the list of documents for review and analysis now that all students have them. As a result of these questions and feedback, the following recommendations were made:

- A second round of interviews to follow up on how students perceive the ways in which they receive support. This would also provide the 6 month update.
- A new category/theme of “external motivation for college/social norms” was to be added
- Existing data required “back coding” for barriers
- Peer interviewers were needed for the second round of interviews
- Modified human participant training would need to be developed and approved by IRB so that student co-researchers could take on the the role of peer interviewers

The second round of interviews was completed late fall of 2016 and early spring of 2017, once students had returned and settled in for the semester. Once these interviews were transcribed and coded, the research circle was reconvened for a final round of collective analysis.

On February 24th, 2016, I met with a student co-researcher and reviewed the results of the meeting on the 23rd. He agreed with coding and categories, as well as recommendations from meeting regarding new categories and added themes. The student stated that he was interested in becoming a peer interviewer, and understood that he will need to attend training. We also discussed poetic analysis, and he agreed to help me work on his poem together once data collection is finished. As part of follow-up on the circle’s meeting, I confirmed with the Office of institutional Research that that we have been approved to have faculty co-researcher do a modified human participant training

so that student researchers can also be peer interviewers. I also submitted modifications to IRB application.



Journal Entry 12 (April 2016)

Co-researcher training: To prepare for the modified training, one of our faculty co-researchers, myself and a staff co-researcher, met to develop the human participant training presentation that was offered to all members of the circle. The training was well received and three peer interviewers attended along with 5 other members of the circle. Support was discussed for peer interviewers, involving visual guides for interviews, role play opportunities, and access to my assistance during interviews if needed. There was general acknowledgement that building rapport should be an integral part of the preparation, since it is a “key element of shared meaning systems” without judgment of people’s “knowledge, experiences and feelings” (Knox, Mok, & Parmenter, 2000, 55).



Journal Entry 13 (April 2016)

Member Check: During follow-up meeting with me, peer interviewers provided invaluable feedback about interview tools and documents. I made changes to interview protocol based on their feedback, as well as consent forms that peer interviewers review before they begin interviews. If interviewers encounter responses that are problematic for safety reasons, they will notify me immediately so that I can follow up. At peer interviewer request, it was also

determined that there is a desire to match male identified students with male identified peers, and vice versa for female identified interviewer. Since one student co-researcher will be returning to her hometown after graduation, it will be a bit more complicated for her to do interviews, but she has agreed to come back to GSO in early fall. The other two students will be available in the fall. I will coordinate one more training session with each peer interviewer, to review the final scripts and do more role playing. I will also follow up with IRB to ensure that modified tools are acceptable.



Journal Entry 14 (June 2016-January 2017)

Poetic Analysis: Having some experience with poetic analysis in other projects, I felt comfortable exploring the use of what Janesick (2016) terms Found Data Poems. These are poems that are “found in the narrative, spoken, or visual text, [and] may transform data from the researcher’s reflective journal, the interview transcripts, and any site documents used in a given study” (p.59). In keeping with her observation below, I use poetry to highlight and clarify data as well as my own thinking and experiences as researcher,

Poetry uses the words of everyday life and goes further with these words in terms of using metaphor, possibly rhyme, and various rigorous structures to call our attention to the meaning of life. Poetry is a way to find out what a person means when he or she speaks the words... Why not take the words of the transcript of an interview, for example, the participant in a given study gives us a

good deal of data. Why not take the words of the transcript and transform those words into a found data poem (Janesick, 2016, p. 59)

I worked with Dolphin first in April, to create a found data poem using her interview transcript. I provided the initial structure for the poem, and then met with Dolphin to revise, re-work or re-do it all together. Dolphin edited and made some additions to the final poem. She was very pleased with her piece, and since its creation, has used it in a presentation that we co-facilitated on CER, and at her senior portfolio presentation. This was a powerful experience for me to share with her as a co-researcher, but I also felt some discomfort in the co-writing process because I felt that moving forward, participants could direct the process even more.

Limited analysis occurred over the summer during break. When we resumed in July, I presented participants with an adjusted process which allowed for more direction. That process is described below:

- 1) Interviews were transcribed
- 2) Student participant/researchers were presented with transcripts and offered the choice of using the transcript to inform the creation of their own original piece, or to highlight portions of the transcript that they wanted to use for collaborative piece (all students have chosen collaborative option so far)
- 3) As they reviewed, students highlighted information that they thought was particularly important given the research questions
- 4) The highlighted information was transferred to new document

- 5) Student participant/researcher worked with me to construct the “Found Data” poem, taking into account poetic conventions like line break, repetition, rhythm, metaphor, etc.
- 6) Student reviewed final product, made changes as desired

Poems are presented in their entirety in Appendix C.



Journal Entry 15 (November 2016)

Data Collection- Phase 2: The second round of interviews were completed 7 of 12 cases received the second round of interviews, as some students declined and/or were not able to logistically be present for the interview. I worked with both peer interviewers to review interview documents and role play problematic situations that could arise beforehand. I made myself available to them during each interview, should they have questions. One of the peer interviewers informed me that with one peer, he had to breakdown concepts on several occasions, which required him to go off script. He demonstrated a clear understanding of the interview process, how to modify and how to respond to each individual interviewee. The second interviewer said that she was not as comfortable going off script, and that she was more reliant on the interview structure.

Table 5. Coding-from Categories to Themes

Categories	Basic Themes	Organizing Themes	Categories	Basic Themes	Organizing Themes
Living on one's own/independence Finances Self-improvement/growth	College as path to critical consciousness and living a self-determined life	individual agency	Inclusion/having valued roles in the community	College as path to valued social roles	Societal impact
Career development	College as a path to discovering career interests, learning how to get dream job		Building/maintaining relationships Campus and community involvement Living the college life	College is path to inclusive quality of life, a chance to have "what all students want"	
Supports needed for success	College as a path to interdependence		Access to college Human rights/advocacy/social justice	College as path to social justice	

These final basic and organizing themes were presented to the circle, along with an overview of results presented in a visual format (see figures 8 and 9 on the following two pages).



Final Thoughts/Notes on Limitations

I have included a number of research limitations and/or cautions that come to mind regarding this research here. The list is not exhaustive by any means, but does represent what I believe to be some of the most significant

concerns to address, including: stakeholder vs. researcher needs, tensions between CER and academic research, narrative fraud, and interview concerns.

- 1) Stakeholder vs. researcher needs within community engaged/participatory research process- I have already encountered the tension between my expectations as lead researcher, the organization's needs, and the desires of the students- with the idea that "what constitutes success in the conduct of the project, is likely to differ" between researcher and stakeholder (Mackenzie, Tan, Hoverman & Baldwin, 2012).

When I initiated the research circle, I had already determined the purpose of the study, as a way to inform a new credentialing process for the program. Initial discussion, however, resulted in a different focus that will likely lead to unexpected recommendations. Reflexivity was paramount regarding this potential limitation. When I realized that there was a disconnect between my wants and the group's wants, I had to let go of my preconceived ideas about what we were going to explore.

Themes related to Individual Agency

The most predominant themes that came forward from the data relating to personal growth as a result of individual agency



Critical Consciousness
The act of coming to a self awareness that leads to active change



Career/Financial Stability
The ability to participate in desired career and develop financial security



Interdependence
The ability to identify where one needs support, make arrangements for support, and give of own strengths/skills

Research Question 1: How do students define personal growth in college?	Research Question 2: Are students getting the support that they need to achieve growth?
<p>Critical Consciousness</p> <p>If you're different, you're treated horribly. They assume I'm gonna act a certain way. I don't want my parents always helping do this, do that. Students need room to express themselves. I came to college to try things that are new to me. Now I feel accomplished. I've been given the power to know my rights. I can make a change in society.</p>	<p>Supports are present</p> <p>Students have described a multitude of ways that they are using coursework, campus participation, program and natural supports to learn about themselves and build self-determination skills.</p>
<p>Career/Financial stability</p> <p>I want a career that focuses on things I enjoy. Excited about taking computer classes and other classes that will help me get a job. I'm still shooting for meteorology. In college, I'm learning how to make money and run a company. My internship prepared me for the paid job. I was doing volunteering and an internship, but I wanted a paying job.</p>	<p>Some supports are present, some are not</p> <p>Students have described a number of ways that they have been able to begin exploration through internships, but there is little evidence of effective support to capture dream employment at desired level.</p>
<p>Interdependence</p> <p>I want a career that focuses on things I enjoy. Excited about taking computer classes and other classes that will help me get a job. I'm still shooting for meteorology. In college, I'm learning how to make money and run a company. My internship prepared me for the paid job. I was doing volunteering and an internship, but I wanted a paying job.</p>	<p>Supports are present</p> <p>Students have described numerous ways that they have identified and utilized support required to live more autonomously- they have also described ways that they themselves have given back to individuals and their community.</p>
<p>Connecting to Theory Critical consciousness, self-determination, career "discovery"</p>	

Figure 10. Themes (Full Graphic)-Individual Agency

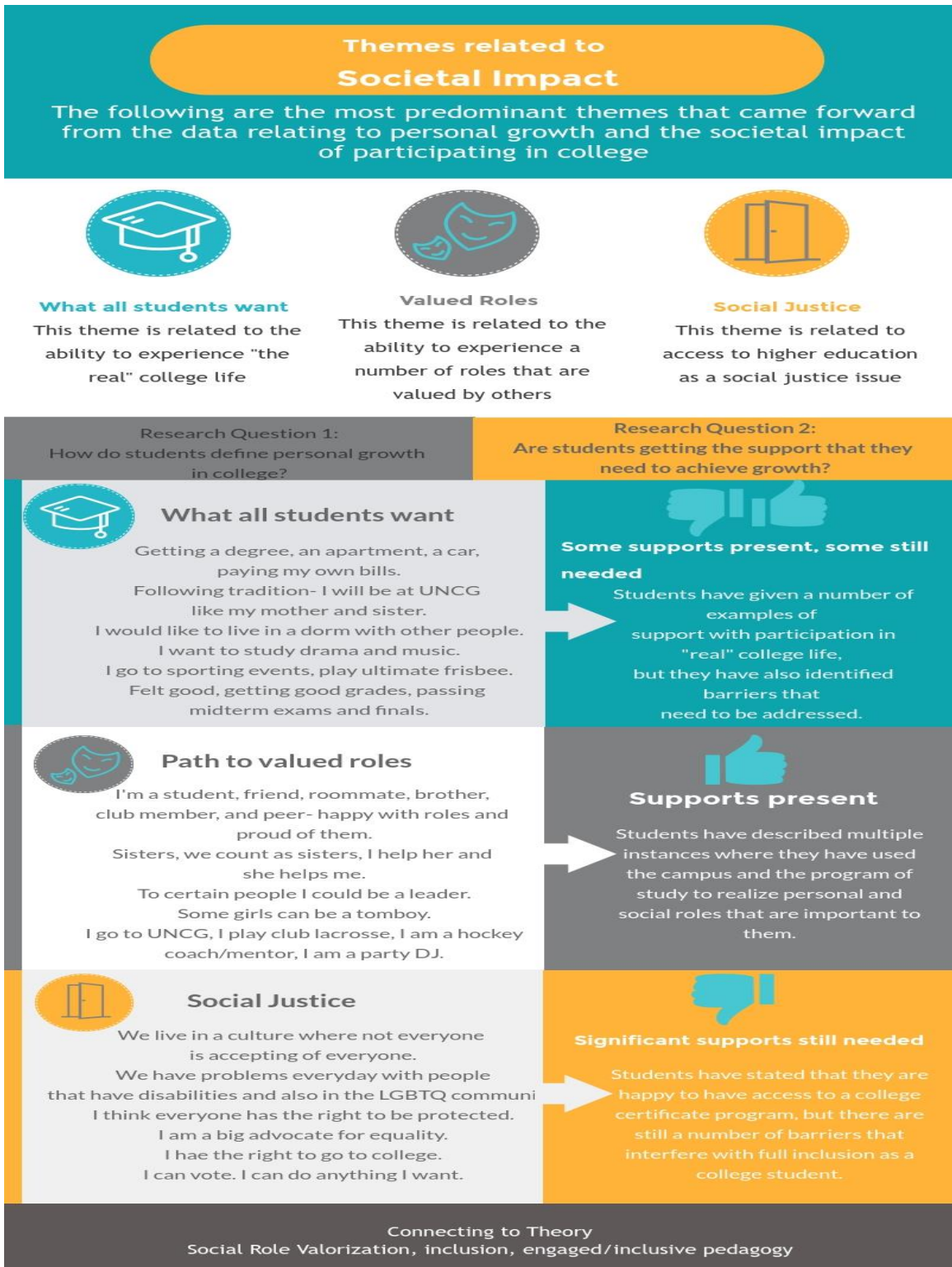


Figure 11. Themes (Full Graphic)-Societal Impact

2) Incompatibility of CER/PAR with “academic” research?- Within the field of education, there has been overwhelming preference for “scientific” research that has been “vetted by the international educational marketplace” and is objective and neutral (Berman, 2008). As I have completed this research, and have participated at scholarly PSE conferences where the special education model is most predominant, I have found this to be so. The rich tradition of emancipatory research that is the hallmark of disability studies, does not seem to have as strong a presence, and it has been my experience that traditional, empirical approaches and even some qualitative research that does not include stakeholders in research design and decision making about the research process are most valued/respected.

Community engaged research that is reflexive and transparent about researcher positionality, and seeks to share power and co-production of knowledge with community members challenges these traditions. These goals however, may not align with the peer-reviewed journals that are most respected in the field. As the project moves towards the reporting of findings, there may be limitations regarding its “publishability” in such academic journals, that it may not “qualify as research output” (Berman, 2008). It is my hope that the expertise of the circle member from the National Technical Assistance and Coordinating Center for postsecondary education programs for students with ID, Think

College, will help open access to publications that are supported by the center.

There is commitment from all of the circle to push forward with approach, even though it is “outside of the box,” as well as acknowledgement that the potential benefits from the research outweighs this concern.

- 3) Mitigating “narrative fraud”- This refers to research that overstates based on “flimsy” evidence, that ignores local effects, and “cherry picks” data (Cousin, 2005, p. 426). There are a number of strategies to use to limit the impact of this phenomenon, including member checks, reflexivity, transparency, the use of thick description, and an “ethic of caution” when it comes to making generalizations (Cousin, 2005). These methods will continue to be used throughout the following stages of research to decrease the potential of this occurring.
- 4) Interview concerns with participants with ID- Research involving participants with severe disabilities suggests that a period of observation is necessary before initiating interview sessions, to develop rapport and familiarize oneself with different styles of communication (Spradley, 1979). Biklen & Moseley (1988) identify the following cautions for interviewers, misunderstandings, tendency to please the interviewer, discomfort with institutional environment, and tendency to answer with the same thing over and over as issues that frequently arise for interviewers working with participants with ID.

My role as director and my experience working with people with ID help to mitigate some of these concerns. I know the students well, and have had time to develop rapport and familiarity with communication. I understand how to break down information/questions/requests into smaller concrete pieces, and how to ask questions in a variety of ways to decrease misunderstanding. Interviews were held on campus in a building that is comfortable to students, where they frequent and also have class. Peer interviewers were used to address the concern about authority and the tendency to want to please the interviewer.

I believe that the poetry presented in the following chapters and in Appendix C moves beyond these concerns, responding to the call for meaningful, authentic data that has great potential to inform scholarship within the PSE community

CHAPTER VI

DATA ANALYSIS RELATED TO THEMES OF INDIVIDUAL AGENCY

Data analysis in the next two chapters represents two main layers of analysis: thematic and poetic analysis. The thematic process was fairly standard in the ways that we applied codes to all data, determined categories based on those codes and then identified related themes, but also differed from traditional approaches in that analysis was not completed by one “expert.” Although I did facilitate the process logistically, a role agreed upon by the circle, I engaged other members of the circle in the analysis as co-researchers.



Figure 12. Themes(Partial Graphic)-Individual Agency

The themes that are presented were developed collectively with involvement from a small group of circle members, including myself, who coded raw data into categories and potential themes, which were then presented to the larger circle for further analysis and confirmation (see chapter 5 for coding tables).

In addition to my responsibility for overseeing the completion of analysis, the group agreed that one of my other primary responsibilities would be connecting theory to findings. After reviewing the data and researching theory and broader concepts, I presented the circle with possible theoretical connections. Final themes in connection with agreed upon concepts were discussed and finalized in our final meeting, and are presented in the graphic above as well as in figure 10. These themes became the framework that I used to help organize the poetic analysis process.

As described in chapter 4, found data poems were created with each participant, pulling text from their interview transcripts. In essence, students acted as co-researchers by taking raw data (their transcripts) and synthesizing the most important concepts in relation to the research questions, as I provided technical support regarding the construction of poems. I then used these poems as part of the foundation for my own larger “found data poem,” presented in the far left column. Using the same process that I employed with student participants, I pulled research journal entries, text from documents that we reviewed, and text from theoretical resources together in one document, and then highlighted what I felt were the most important contributions in light of our research questions. This

process of using poetry to present findings is also known as ethnographic poetry (Fernandez-Gimenez, 2015).

Within the poetic analysis presented here, student voice is always identified by the use of bolding in the text of the writing, to ensure that within my poetic weaving, that voices other than my own are clearly identified. In the column on the left, student voice comes directly from the raw data, excerpts from the documents that we reviewed, which were incorporated into my own overarching found data poem. The second column in yellow, includes excerpts directly from the student's individual *found data poems* (sourced from their interview transcripts), creating layers of student voice. By including large blocks of student poems, I think that it gives the reader a chance to get a sense of individual voices in a way that is not so directly co-mingled with mine as the author. To further this goal, I have included full found data poems in their entirety for each student in Appendix C, so that readers can engage with their voices directly and can experience the full blown poetic for each.

The bolding and text box strategies were used to provide immediate visual recognition of student voice, within the larger discussion of results. I have also included "journal boxes" to the far right of the page, as another layer of analysis, as another representation of my own voice. These boxes provide a space for me to be reflexive as a researcher. This was an unwieldy process, as each participant required review and analysis of 8-10 multiple page documents and lengthy transcripts. I use the graphic in figure 13 to give a visual sense of the

process, to highlight the “distillation” that was required to arrive at the following results. In the following sections, theoretical connections/concepts are discussed both at the beginning of each theme, as well in the body of the poem.

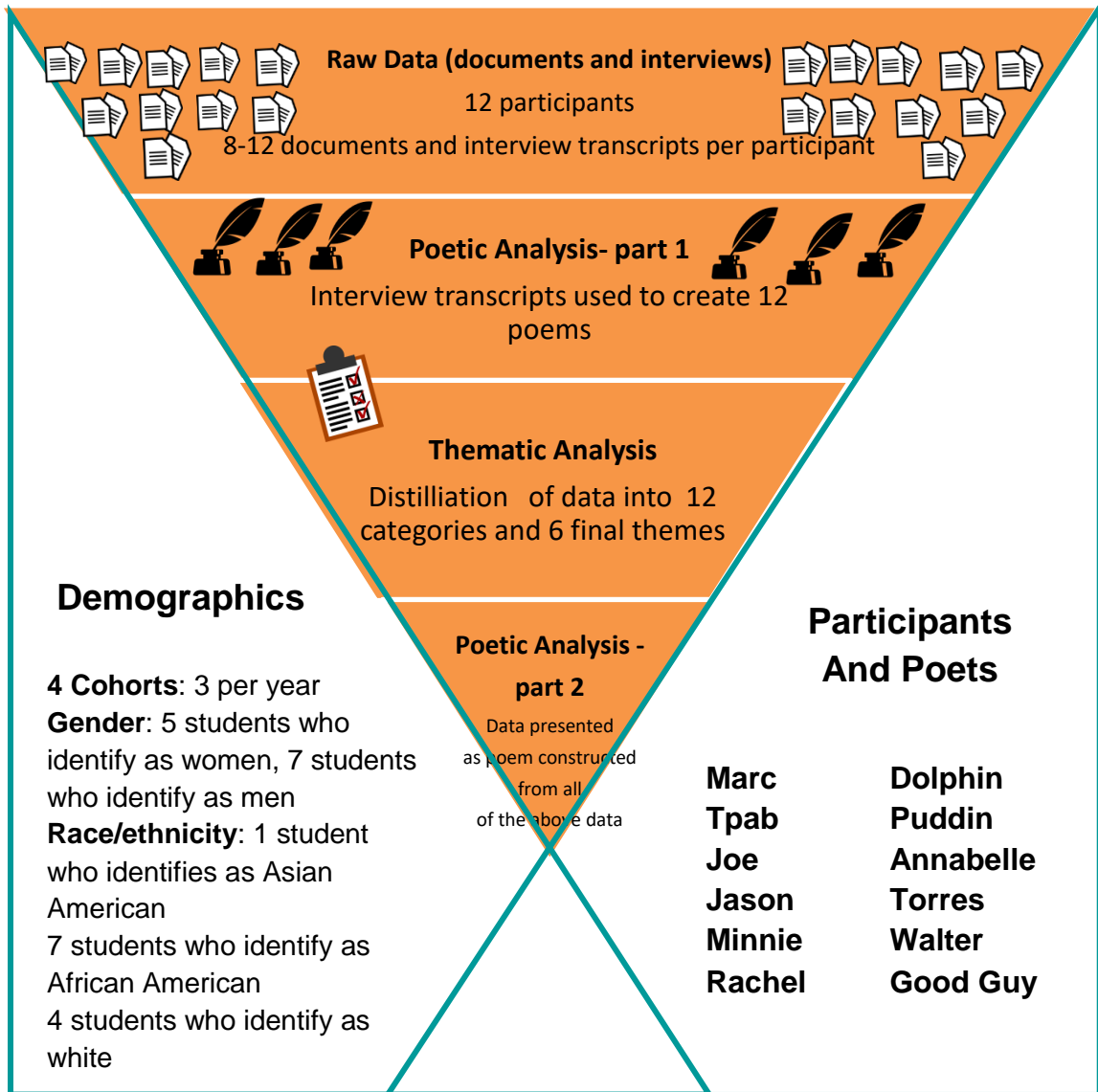


Figure 13. Visual of Data Analysis Process.

Theme 1 (College as a Path to Critical Consciousness)



One of the most predominant themes to come forth from the data, relates to the concept of college as a platform for self-realization. I believe that the ways in which students spoke about this important goal, align directly with Carlson et al's definition of critical consciousness as “the impetus for changing attitudes of personal responsibility and behaviors or participation based on the ability to perceive social reality as a consequence of individual choices” (p.838). They identify 3 elements of this process of attitude change, that I also believe are presented in the data: emotional engagement, cognitive awakening, and intentions to act (p. 843).

For the purposes of this research, emotional engagement involves a response to feelings of being presumed incompetent (this can manifest in a number of ways and for a number of reasons). Essentially, students begin to acknowledge deficit based thinking. Cognitive awakening is defined here as the growing recognition of what Carlsen et al. calls “the responsibility and complicity in the social reality of their lives” (p. 844). Students begin to identify the players involved in acts of discrimination, including themselves and others (p. 845). This process of awakening guides future actions and/or intentions to act, providing the student with an ability to see a new, self-determined future. These concepts are similarly framed by Wehmeyer (1996) as the process of self-realization, which includes self-determination. “To be self-realizing,” Wehmeyer says, “students must have comprehensive and accurate knowledge of themselves in terms of

their personal preferences, strengths, values, and needs, and be able to utilize this information to set goals and make choices and decisions” (p.17).

Data Analysis

Emotional Engagement
first stage towards
building understanding of self
and role in shaping life’s
reality
students feeling
responding to
engaging with a world
that sees the can’t
the won’t
the don’t

JOE wanting to be
**a better adult
than I am** now
acknowledging the reality
of **disability and growing up
of how hard it is to fit in.**
**If you’re different,
you’re treated horribly**
he says,
expressing his
disappointment
frustration
awareness of “restricted”
ideas of self

PUDDIN
discontented with limitations
and dis/belief
and presumptions
eager to push past
restrictions like JOE
making her feelings known

**I guess from who I am
they see that
my cerebral palsy
and stuff
they see that
they treat us differently
because they
they see who I am
and then automatically
they assume
that I’m gonna act a certain way
making me real quick
“realize who my real friends were”
(JOE)**

**sometimes
I wanna keep living
in a house,
but my aunt,
she just afraid
I wanted to live
down here
but she want me
to move back home
have to tell her
I want to go
to hair school
go back to hair school
maybe somebody
can help me
someone in the program
(PUDDIN)**

Emotional engagement requires an eye to understanding the world as it is, having an awareness of inequities. In my experience, folks often dismiss the ability of people with ID in having this level of awareness. That is one reason that I think that this data is so important.

Note Joe’s repeated use of “they” - he is clear that he is being “othered”

Here Puddin illustrates the tension between wanting to challenge restriction, and acknowledging a need for support, which is often viewed as proof of incompetence.

about not being challenged
to meet her capabilities
demanding that we unrestrict
our imaginations
and expect more

GOOD GUY's fears
about **taking big tests
in my classes,
eating in a cafeteria
with a lot of food
that I don't like,
and staying out of Durham
for a while**

PUDDIN and ANNABELLE
struggling with fears
of being alone
and moving to GSO
on their own
highlighting the internalization
the doubts that come
with few opportunities
to test strengths
when crushed by the
tightening arms
of families like PUDDIN's
who protect to the point
of paralysis

Students telling us
by word and deed
that we
our program
needs to back off
walk the walk
practice what we preach
and trust in their strengths
TORRES admonishing

A critique of program
limitations that
demonstrates ability to
assess and determine
efficacy on Puddin's part.

**the stuff that we're
learning,
it seems like the stuff that we're
learning,
we learned from freshman and
sophomore...
it would be better if they just
changed up a little bit
not too hard, but different
different stuff
like with the management and stuff
like that,
I wanna see something different
(PUDDIN)**

The revelation by Torres was
startling when I heard it because it
reminded me of just how much we
have grown in philosophy as a
program. A sophisticated critique I
think, not only of our program but
of the broader service system.

**I think when Beyond Academics
first started,
everyone was used to giving people
you know extreme supervision
like they were responsible for you,
this is the way that medicaid was
set up at the time
so you didn't really have any time to
breathe like
they think they are restricted in a
way
but they're really not (TORRES)**

expressing his desire
for **less intense supervision**
so that students have
more room
to express themselves
without being told
do this, do that,
do this, do that
letting them voice their...
have their voice

RACHEL
voice clear
about her understanding of
contrast between
lack of opportunity
and agency
bridging stages
of emotional engagement
to cognitive awakening

Cognitive Awakening
Next stage to self realization
students processing
thinking through
their own complicity
and responsibility
in the state of their lives
TORRES thinking through
reception from college peers
regarding race
and his responsibility
to counter

JOE
acknowledging power of
individual agency

Before college
not doing what I want to
and not going where I want to go
was not working
now I feel accomplished
by getting good grades
being in school
almost finishing school (RACHEL)

Being able to come to an understanding like Rachel's, is, like Carlson et al. (1996) argues, a crucial first step to self-realization. Students who are not able to do this, who are happy to have their families continue to tell them what they should want and do with their lives generally struggle with the level of self-direction that the program and "real life" requires.

I was raised by an interracial family,
and you know
I received a lot of criticism for that
they thought because I was raised
by a white family,
they thought that I was better than
them
calling me an Uncle Tom and a sell-
out,
that is very offensive
I don't think I'm better (TORRES)

I went to a high school,
high school told me I would never
have a future
or that I would never go to college
and now

in the face of society's
restrictions
as he says

**Positivity is essential,
even on your worst day
keep your head up
because each day
you will become closer
to reaching the dream
that you want**

TORRES connecting college
to pushing past boundaries
imposed by others
awakening to his own
power to change course
take a different path

TPAB highlighting his perception
of difference

between the freedom
and challenges
that come with college
and home
small town

where going home for break
feels very different

is boring

he says

**being bored in college
is different from being bored
at home**

there's always something there
in college

**that can keep me occupied
(TPAB)**

MARC showing a more
nuanced insight into
his experiences on break

**I've been given the power to know
what my rights are,
to know sociology
to be a scientist,
kind of a certificate
in social justice
I came here
its like they thought
I didn't have the qualifications
to go to college,
and they were making all these
assumptions about me (TORRES)**

Torres claims his power here, his ability to impact/change his life even in the face of discrimination- use of the word "now" a clear indicator of awakening.

**When I go home
I feel homesick
its very complicated because
when I was a freshman
and I was living on campus
and I came back home I felt like
like I don't feel like being here.
It felt different
because I was
a lot more independent
and if I come back home**

**I don't want my parents
always helping me
do this, do that
depending
on my grandma
my grandma is
always helping
me out**

**it is very hard
to let go.
she says that my problem is her
problem (MARC)**

Awareness of such "familial" complicity is crucial for the student, but also for the family, who generally holds significant power that can impede growth when wielded with impunity.

an understanding
of family complicity
and the workings of “caretaking”
founded in presumptions
of in/ability
supporting student voices
like MARC’s
a difficult programmatic
balance to maintain
when parents hold
the purse strings
and sometimes even legal rights
TPAB
acknowledging
a fresh understanding of self
that college has given him

WALTER and ANNABELLE
speaking respectively
to awareness of personal limits
nervousness deejaying
in front of people
difficulty with
meeting new people
in gospel choir
but also understanding
of their own role
In **working hard,**
learning to be tough
Their responsibility in confronting
Their own
the end result of that work
A **blessing**

TORRES
demonstrating
his own awakening
describing

**I guess being at UNCG
it has made me kinda
a lot of people think
that I’m kind of shy
a little bit,
being up here
at UNCG**

**it has become easier for me
to actually show my true character
and everything...
UNCG like... very diverse
and everybody is being themselves
and so I can be myself here
and be happy (TPAB)**

**They would come
to our apartment
and just sleep at our place,
which is very rude,
I mean why would you come to our
apartment and sleep
the whole time you were supposed
to be working...**

**I guess you know when you're 19
and you're in college
and you're just adjusting to it,
you kind of go through a lot more
stress
you have some maturing to do..
you know now,
I would just ask them to leave
I would say, I think I refuse services
today
you can just leave,
and I'm probably going to let your
supervisor know you were falling
asleep at work (TORRES)**

Significant again
because of
presumptions that
students are unable to
determine or articulate
what being
themselves even
means.

CCS

support staff who
**weren't helping us
helping us naturally
get connected
who
were just coming over to
boss us around.**

directly attributing growth
and maturity
to opportunities to speak up
and speak out
about needs

TORRES

so beautifully transitioning
from awakening
to action

Intentions to Act
final stage of consciousness
intentions to act
to actively
be the change
to act as
the causal agent in one's life
(Wehmeyer, 2016)

Opportunities for
self-determination
in college so essential
for students with ID
because of fewer chances
to make choices
and express preferences
than non-disabled peers
coming from home, school,
community environments
that limit self-determined lives
(Wehmeyer, 2016)

**I would say the big changes are I've
matured, you know,
to the point**

**I was starting to express
my identity**

**I guess you could say,
I'm more straight forward
than I used to be
and when you're more open
when you're nice about everything**

**I've learned that sometimes
you can be taken advantaged of
its good be humble,
but at the same time**

**it's good to be straight forward,
I want to say**

**that I chose to come to this,
coming to college
to study ICS for a good cause,
being in the ICS, I just learned a lot,
that I could make a change in
society**
(TORRES)

Ohtake and Wehmeyer (2004)'s framing of self-determination is reflected in the data including, acting autonomously, regulating self, initiating and responding to events in empowered way and realizing self, (p.170).

Acting autonomously
MARC wanting to learn
to advocate for doing things
the way I want to do it
JOE affirming
that he came to college
to be more independent
RACHEL saying
**I look forward to doing
what I want...
and learning so I can do things
in the future**
PUDDIN sharing in her
application that she wants
to learn **how to live and
do more things on my own**
JASON confirming that in college,
he is indeed
learning to live on my own
Student responses illustrating
the importance of doing things
living on their own
and college's role
in that learning

Self Regulation
Self-assessment
students being outside
of themselves
enough to evaluate their own
growth
JOE
speaking of his ability in college
to **slow down and think about
the situation** In order to
fix it by myself
TPAB understanding a tendency
to let others take advantage

I've noticed that from my
experience,
when I meet people in person,
I never can really relate to them
you never know if they like you as a
girlfriend
or if they like you as a friend
on the dating site they'll tell you if
they want to be friends
or if they are looking for
relationships,
so when you ask someone out on
the dating site
you don't get the awkward question
is it a date?
I was just wondering is it something
that I'm doing wrong?
I'm just doing what all the other
guys do
but something is just not right
(TORRES)

In high school, students with ID are often taught life skills in an isolated setting that offers few chances to practice what they are learning in the real world. Data suggests that students view college as an important "life lab" that gives them such opportunities, and that they feel confident in their ability to carry those skills forward into life after graduation.

and seeking help
from the closest person
he can trust
TORRES assessing himself
in relation to others
trying to determine what
he needs to grow

Empowered responses
engagement with the world
third component
of self-determined living
JOE affirming
His own agency

**I open up to my parents
and afterwards
I am able to make
a clear decision**
JASON saying
**my dad
he just pays the check
I make decisions about my life
myself**

GOOD GUY feeling confident
in his ability to be
**In charge of deciding where
and who he lives with**
ANNABELLE's pride
in overcoming at work
a struggle

GOOD GUY who is proud
of **sticking to his right
to say no**
who
in a beautiful moment

**I decide my goals
cause I'm my own person
what I feel good about
is that I'm a sophomore
which I am really happy about
accomplishments
I normally have a talking to my
grandma, family members,
spending times with them
before I start to going back to
college
I feel good about that
I feel most proud of that
I'm living in spartan village
and that I'm being more
independent
(JASON)**

**Playing the piano
for the elderly
reaching my dreams
learning how to play
in that kind
of environment
It wasn't easy
I was nervous
but I kept on going
and in the community
taking the bus
it was challenging for me
because I had to be brave about it
said to myself
you need to stop being a baby
and do it
and now I love the bus (Annabelle)**

**Feel good about overcoming autism
statistics, definitely
A few people who say
You're not gonna**

I was struck by what I see as Jason's contemporary attitude about college- it reflects the entitlement era that I would argue is new to PSE, where students have previously been told, "you are lucky to even be here"

of critical consciousness
realized and self corrected
midstatement
that if he is in trouble
he would not **tell a grown up**
but **speak up**
for himself

TPAB expressing a willingness
to move past reticence
I talk to everybody who
wants to know
about my dreams
I mean I can't be shy about it
In a way that makes him
feel good

DOLPHIN echoing that pride
and power
her choice
to pick a path
and make room
for the coming to fruition
the realization
of her full
self
Last piece
of the self determination
puzzle

Self-realization
the ability to bring
self forward
in a variety of ways
and different expressions
RACHEL identifying
singing and performing

make it this far
or make it that far
proving them wrong
feels good
feels like its gonna be a long road
but however way I'm gonna get
there
I'm willing to go for it (TPAB)

I have the right
the right
I have the right
to speak my mind
to speak my mind
about my feelings
to speak my mind
about what I know
to go anywhere
I want to
to take charge
to keep it as it is
its my choice
its my choice to pick my path
to choose what I want to do in life
I do it on my own
I teach myself (DOLPHIN)

I am much more responsible now,
I have learned to get to work on
time from wherever I am,
I can be counted on dress
appropriately for meetings and
interview,
I keep my apartment cleaner
including my kitchen, my bedroom
and my bathroom,
I get my haircut at the barbershop
in GSO twice a month,
I do my laundry (GOOD GUY)

It is frustrating to see
students with an
awakening like
Dolphin's, graduate and
then struggle with a
service world that will
continue to expect
compliance and passive
acceptance of
"professional" and
family feedback,
effectively putting them
right back into a box

as goals for her

**dream to be a
successful person**

GOOD GUY reporting increase
in feelings of

independence

responsibility

social skills

mastery with money

and life

by practicing in college

by budgeting

managing his apartment

joining clubs and organizations

and spending free time

as he chooses

GOOD GUY much the same
realizing college's impact

on self

experiencing joy

fulfillment

in having own place

where friends and parents

come and visit

TORRES

coming to terms with expectations

and acceptance of self

critical awareness

of society's pressure

to shape oneself

according to norms

and his own power

to use college

as a platform

to break free

**you know getting married is not that
big a deal to me,**

**I might just want to date for the rest
of my life,**

**And you know just work, eventually
build a house in the area later on
down the road**

**I already have a place I'm renting,
and I'm moving in (TORRES)**

**like I wasn't really myself in high
school to be honest,**

**I used to wear my pants hanging off
my behind,**

**I used to not speak proper english,
but you know that wasn't really me,**

**I was just trying to fit in with the
other kids at school,**

**you know high school these days
can be like a hellhole,**

**I'm not going to say it the other
way,**

**but when you go to high school and
you are not mainstreamed**

you are an outsider,

And you know college is different

I came here

I chose to come (TORRES)

Data confirming
and answering questions 1 and 2
that students see college
as an essential building block
to critical
consciousness
and realization of self
an important component
of personal growth
confirmation
that they have support
and opportunities to grow
Multiple examples of students
taking advantage of
college environment
to evolve skills and concepts
of self
GOOD GUY reporting that he
**Feels he has good resources
to reach goals**

TPAB confirming that
DOLPHIN agreeing
saying

**I have support
I ask for support
when I need it**

In making decisions
about where to live

JASON feeling respected
big support to follow through
on his choice

Students telling us
again
and again
and again
that they see
they know

**As of right now
everything is good
going the way I need it to be
tryna finish school
and get my education
and get my dream job
I've been thankful for what I have
Since I've been away from it
Like my parents and stuff
Cause now that I'm away from it
It's different from when
I was seeing them everyday
I got more out of my shell
I got more involved
So its independence
It teaches you independence
Its me doing the work
It can't get done without me (JOE)**

I think that Joe provides a beautiful example of the movement required to become critically conscious. He recognizes that having the opportunity to practice self-determination, helped to change his perspective about his world, and that he had to "leave home" to find the space to do so. This is a point that we try to drive home with parents, that having the freedom to direct your life, even what you do on a day to day basis is an invaluable part of coming to understand your own agency.

they understand
and are moved
to take action
to demand change
to alter the course
of predetermined
expectations
and presumptions
about what they are capable
of doing
Significant finding
for program,
families,
and broader community

Theme 2 (College as a Path to Career and Financial Stability)



Integrative Community Studies uses the stages of *customized employment* as foundational framework for supporting career exploration through ICS coursework. This model identifies four stages of career development: Discovery, Job Search Planning, Job Development and Negotiation, and Post-Employment Support (Griffin-Hammis Associates, 2008). These stages have been incorporated into the curriculum with a focus on promising practices in employment support including involvement of family and friends in job search, job development that focuses on matching individual skills with needs of employer not just position, negotiation with employers, and planning strategies that emphasizes choice and empowerment (Migliore, Butterworth, Nord and Gelb, 2011).

Data indicated that students are benefitting most consistently from the discovery stage of career development through the program, as they gather information about their interests, skills, preferences, effective strategies, ideal working environments, etc. The discovery process is an evidence-based alternative to comparative, standardized assessments and evaluation- a person-centered planning process that involves getting to know a person before supporting them in developing a plan for employment (Griffin-Hammis Associates, 2008). College is a natural environment for discovery, but it has also become clear that ICS students, like their peers, struggle with “closing the deal” on jobs in their preferred area of interest.

Data Analysis

College as path
to career development and
financial security
important element
of personal growth
as identified by students
expressing clear expectations
that college enrollment should
result in dream job
and money
enough money
to take care of myself
TPAB says
and a career that focuses on
things that I enjoy
Student experiences
exemplifying
process of discovery

**I'm still shooting for meteorology
from what I heard**
**I have to increase my intake of math
and science**
and I think
another thing I should probably
work on you know
you know
talking more
Just a little more being more open
I think my communication with
other people is good you know.
I think I'm talking more
into like presentations
I chose (DOLPHIN)

key component
of career exploration
college as vehicle for
exploring strengths and interests

Like ANNABELLE

trying new things

to find her dream job
working in an office setting,
working at habitat for humanity
playing music at a senior home
trying the piano
instead of the flute

**Not an easy question,
but I had to play it out that way**
she says

like any college student
taking advantage
of campus environment
to find career focus
learning different things
says RACHEL

**So I can do things that I like
In the future**

acting and singing
auditioning for plays
women's glee club
campus theater
theater classes
trying to narrow down the field
Same for WALTER,
practicing baking
researching business classes
practicing lacrosse
applying for internship
JOE excited
about computer classes
**and other classes
that will help me get a job**

**been interested in weather
Since the third grade
not necessarily anything in high
school or anything (TPAB)**

**I'm taking
ENT 450-Directed Business Practice
so that I can keep learning
about business
In college,
I am learning how to run a company
In college I am learning how to be
successful and manage my money
(JASON)**

**I thought I might
be interested
in media
so I took
a UNCG class**

**called media studies
I gained experience
through Spartan TV.
got the chance to help by operating
the TV cameras and soundboard.
I liked this type of work but I prefer
to work with cars
like I have a job at honest one auto
shop as an auto shop assistant
I chose it
cars, I'm interested in cars and stuff
I looked around for it and chose
honest one the place
it's convenient to my home,
my apartment, and uncg
they're nice, get paid
want more hours
After I graduate (GOOD GUY)**

We often get push back from faculty, asking "what do students get out of being in class?"- outside of answering the "same thing that any other student gets" Jason and Good Guy demonstrate clearly how access can impact career interests

PUDDIN visiting a hair school
making wigs,
building and pricing a portfolio of
hairstyles,
**I would like to get
my own hair salon
one day,
after I own my hair salon
I can become a hair teacher
I can be a fashion consultant
working in a film setting
(PUDDIN)**

GOOD GUY
Using his coursework
to pinpoint his career
in auto mechanics
use of internship to
increase knowledge
of mechanical operations
determine areas of specialty
identify and become familiar
with different makes
and models of vehicles
resulting in paid job
affirming his experience
**My internship prepared me
for the paid job
and I will be able to live on my
own with a good paying job**
Like JASON, who wants to work
at the bowling alley
and **earn more paid checks**
saying **not to be broke
is important to me**
both making a connection
between work
and financial stability

**Working at the bowling center
something I have to do
A job that I want
want to keep on helping out
Important to me
Figure out goals in life
Steps to dream job
i've taken finance class
entrepreneur class
the internship class
I say its been very helpful,
and I think I'm getting better...
(JASON)
the internship from last year
at Spartan Trader
sell things, sell product
did a little bit of customer service...
helping with the manager
learned important things
it was a good experience (JASON)**

**My dream job is I want to do
business
entrepreneurial
owning my own restaurant
I decided that
I like cooking
I was looking on the internet and
figuring out what steps
I'm supposed to do for the business
mostly I did that on my own,
and I got help from my uncle, he
owns his own business
I want to take classes
building your own business
any way that I can learn how to
build my business (MARC)**

RACHEL demonstrating understanding of financial planning the need to **save money, research cost of living to be able to make decisions about move to NYC**

ANNABELLE equating success with money management **To be successful you have to use your money right**

MINNIE summing it up highlighting connection between Job and money Job and self-worth Job and involvement Job and fulfillment still showing sadness that dream job at Disney World did not come to fruition ALL students articulating desire for paid job very few with evidence of it happening JOE, JASON and DOLPHIN all voicing frustrations with limited progress

Data positively showing that students see career development and financial security as valued elements

I was doing volunteering and an internship but I wanted a paying job A job that pays money and now I have one a job that gives me something to do that makes me feel great that makes me feel important I like being independent Living on my own Making my own choices In the future, I want to get married and have a family But I am not focused on that right now Right now I am focused on my two jobs being independent and living the life that I love (MINNIE)

Minnie's journey is still difficult to digest, as working at Disney World was a possibility for her- but without family support, her dream died on the vine...

Lack of data on success with obtaining "dream jobs" could be attributed partially to status of participants- as college students who have not entered the job market yet. This is an area, however, that needs further evaluation, given the student's desires for stable career and finances, and given federal mandates like the Workforce Investment Act (WIOA) that are going to require employment providers to partner with colleges and universities with PSE programs to help students find employment.

of personal growth
in college
But providing few answers
to research question 2
beyond discovery
lack of data indicating
the how
the way
that supports are being used
to get that dream job
that they have discovered they love
important finding
for programmatic consideration
changes to be made
so that supports are clearer
better understanding needed
of existing
barriers
feedback from graduates
who can shed light
on what worked
and what didn't

Theme 3 (College as a Path to Interdependence



Independence has long been promoted as the absolute ideal for people with ID, underscoring beliefs that reaching some “normalized” state of autonomy is what allows for inclusion into the community. Like black feminist scholars however, I think that recognizing the importance of interdependence is a better hallmark for inclusive communities. Interdependence is defined by Webster as “a reciprocal relationship” between “objects or individuals or groups” (Webster, n.p.). As such, one could argue that interdependence, rather than independence

is at the heart of inclusion, because it requires that involved parties find mutual value in one another.

Paulo Freire (1974) has argued that true “integration” requires that an individual have an opportunity to connect with their capacity to adapt to “reality plus the critical capacity to make choices and to transform their reality” (p.4), the backbone of what Carlson et al. (1996) have defined as critical consciousness. The act of coming to know the world, one’s location in it and how to impact that world, is, as Freire tells it, a function of relationships. “To be human is to engage in relationships with others and with the world,” he says (Freire, 1974, p.3).

Although I think that it is important to be clear that “engaging” in relationships can look very different from person to person, and should not be reduced to any one definition, I see the power of Freire’s claim. As students become more aware of their relationship with the world, and how they are perceived and/or treated by that world, they can begin to identify their own capacities and needs. This most frequently means coming to see that they have been presumed to be incompetent in one capacity or another, and have been treated as such by others. As they challenge these presumptions, and awaken to their “own selves” they increase their ability to move from dependency to interdependency, as Carson et al. (1996) claim. Proof of this “coming to understanding” was prevalent in the data.

Towards interdependence

from dependent
to interdependent

students affirming
that they recognize the need
for support
to be able to realize
self
support with
classwork
participating in school functions
and dorm activities
JOE saying
“They help me
with the move to real life”
the move to real life
a significant statement
Success determined by
TPAB, JOE, RACHEL, JASON
acceptance of support
with
initiating new friendships
organizing itemized budgets
completion of assignments
transportation and safety
JASON expressing desire
for support
to decrease anxiety
about post graduate life

Students identifying
avenues of support
family, friends,
teammates, coaches,
mentors (WALTER)
Instructors, advisors, teachers,
social workers, tutors
(ANNABELLE)
Pastor, staff, co-workers,
credit union, uncg, employer,
church (GOOD GUY)

I’m not sure about the living on my own

**I’m not so sure about it
cause living on my own I would
have to pay the bills...
the electricity bills, utility
its just... thats gonna be,
not easy for me
the finance piece,
I think it’s the money
Makes me nervous
about graduating
the money (JASON)**

**Mostly with friends
and family**

**I met here at school,
a few back at home
I’m happy with what
I’ve got but you know
it’s like friends come a
it is what it is so...**

**cause everybody is not going to be
your friend
my parents and family definitely
support me
and a few like maybe a few close
friends**

**I can count on family
sometimes friends
because I trust them
My natural supports
My mom my grandma
my family and my friend who lives
in florida in Key West
I trust very much
That is very important (MARC)**

I was really struck by a phrase that Joe used in his interview, explaining that he needed supports with things like cleaning, organizing and cooking to “keep up with himself”. A perfect statement to illustrate Freire’s (1974) idea that relationships lead to agency...

Identifying needs
 assisting with cleaning,
 roommate conflict,
 adjusting to new home,
 connecting to community,
 supported employment
 (GOOD GUY)
 Taking medication
 (ANNABELLE)
 Making friends that treat me right..
 understand me (PUDDIN)
 ANNABELLE offering insight
 Give and take of family
 Relationships during her breaks
 MARC acknowledging his strength
 and reciprocal nature
 of supportive relationships
I would like to help my mom
 He says
**like pay the bills,
 that kind of stuff,
 I have to be responsible**
 even as he recognizes needs
 and barriers
**I want a romantic relationship
 but not having a counselor
 to help me with my problems
 gets in the way**
 and frustrations with supports
 that try to control

PUDDIN experiencing
 much of the same
 illustrating the tension
 between accepting help
 and personal agency

TORRES speaking to the

**Not respecting my rights
 sometimes my family does that,
 And then I don't like it
 Cause it feels like I'm not taking
 care of my own
 I talked to my grandma
 and my grandma says that I don't
 do it. I don't do that
 But sometimes
 she does (MARC)**

**I see my family
 I talk to them
 on the phone,
 but I don't see them
 like that
 just the holidays
 now that I'm comfort
 I'd rather see them on the holidays
 or sometimes on the weekends
 they support me
 if I need groceries or something,
 then they'll like come down and
 help me out
 because my food stamps they cut
 my food stamps low
 I make decisions by myself, but
 they be trying
 they think that I'm not ready to be
 independent
 they be babying me too much
 (PUDDIN)**

In my experience, parents, families and human service professionals struggle with understanding that being interdependent does not mean that someone is incapable of directing their lives, and is in fact quite the opposite- this is a point that we need to bring home more clearly in the education and consultation that we provide to them...

\naturalness
of interdependence
to Freirian ideas
about relationships
and how they support
the move
towards
agency
and
action

Challenging the program
to be mindful
accepting of
clear about
their role
when it comes to
that uneasy balance
between supporting family
dynamics
and speaking out
against ties that bind
too tightly
for students
to grow

Data offering positive evidence
in response to question 2
GOOD GUY stating that his suppo
are his choice
and that he is
**able to accomplish goals
with support staff**
MARC affirming clearly
**I decide on support
they are working for me
so far
would not change**

**I guess you could say
it's really not bad to have your
family help out
it's not a lack of independence
I'm not saying to have your family
tell you who to date
and all this other nonsense,
I was just saying some people say
hey I want to live with my parents
because it's free rent (TORRES)**

**I have friends of all ages
I consider them to be
my natural supports
my friends at the ministries
we kind of believe
in the brother sister thing
a deep down belief
a personal belief
is the best way
to phrase it
(TORRES)**

**My staff
they help me
with stuff,
they do it with me,
help me
take me grocery shopping
sometimes
help me look for apartments
to live in
Living alone
I feel good
I have the right number of hours
(GOOD GUY)**

Self Determination Theory
is a reflection of Freire and
Carlson et al (1996),
asserting that personal
agency is impacted by
understanding the
congruence of "one's basic
needs and social contexts"
(Shogren et al, 2015). I
believe that the data
shows that college helps
students learn what
supports they need to
"transform their reality."

as of right now
reporting that
nothing really
is getting in the way

JASON an echo
saying
I decided on supports
and they do work for me
building my self-confidence

MINNIE sharing similar sentiment
as she confirms
friends who see her
and treat her
with respect
as she defines it
Romantic relationships
exception to the rule
a barrier to many
girlfriend
I'm still looking for one
says JASON
not easy to find
important
there's just too many of them,
I tell my gut to get one
but I don't know
RACHEL in agreement
saying
I want to be in a relationship
but need help with that
TPAB taking the discussion
A step further
To identify his own anxiety
With disability identity
Seeing that is a barrier
To romantic life

I like the person that I work with
My support,
I'm good with
what I have right now
a lot of close friends
Friends who treat me
nice and sweet
Friends that I spend time with
And who I love (MINNIE)

I have noticed that students who work with us as peer mentors seem to have a good balance of perspective regarding interdependence. I must wonder if having a role as such helps them more clearly experience the reciprocity of supports...

Girlfriend
that's still in the works I mean
It's important
It's not a barrier
but I can possibly see it
as being one
maybe telling them
that I'm in this program
that works with students with
disabilities
Not saying that it is one,
but I kinda see it being one (TPAB)

I am a good peacemaker to my
friend when she needs me
When she breaks down
I can help her solve the problem...
It depends on the what the problem
is (A

Annabelle acknowledges her capability and value here, as a peer support who can help with solving problems. She consistently recognizes what she is able to offer her friends, family and community throughout her feedback.

TORRES offering a final
complicated take
on inter
dependence
and interaction
illustrating a
keen awareness of the
policies,
rules and regulations
that strip folks
of their humanity
and sense
of agency
offering his own thoughts
on the importance
of valuing
reciprocal support
as a part of the
human
condition
priming the pump
for the next chapter
analysis of society
community
university role
in growth.

I get concerned about the number of times that we hear students refer to their staff as their worker, as it perpetuates this idea of unidirectional support and dependency rather than mutual interdependence. Torres speaks to this so beautifully here...

**you know some services
I have to have
it's not really optional
but I will tell you this
an interesting perspective
some people really don't know
there are some progressive people
that think services and friendships
go together
and that's a controversial topic
if you work with someone
you should be able to be friends
with them
that's what they believe
I kind of agree with them
I think some agencies
they don't want professional and
friendships to mix
but I think at the end of the day
here's what I think
we are all human
and professionalism is good
but I think at the same time
sometimes we kind of let it
dehumanize us
and that is something
that I really don't agree with
(TORRES)**

CHAPTER VII

DATA ANALYSIS RELATED TO THEMES OF SOCIETAL IMPACT

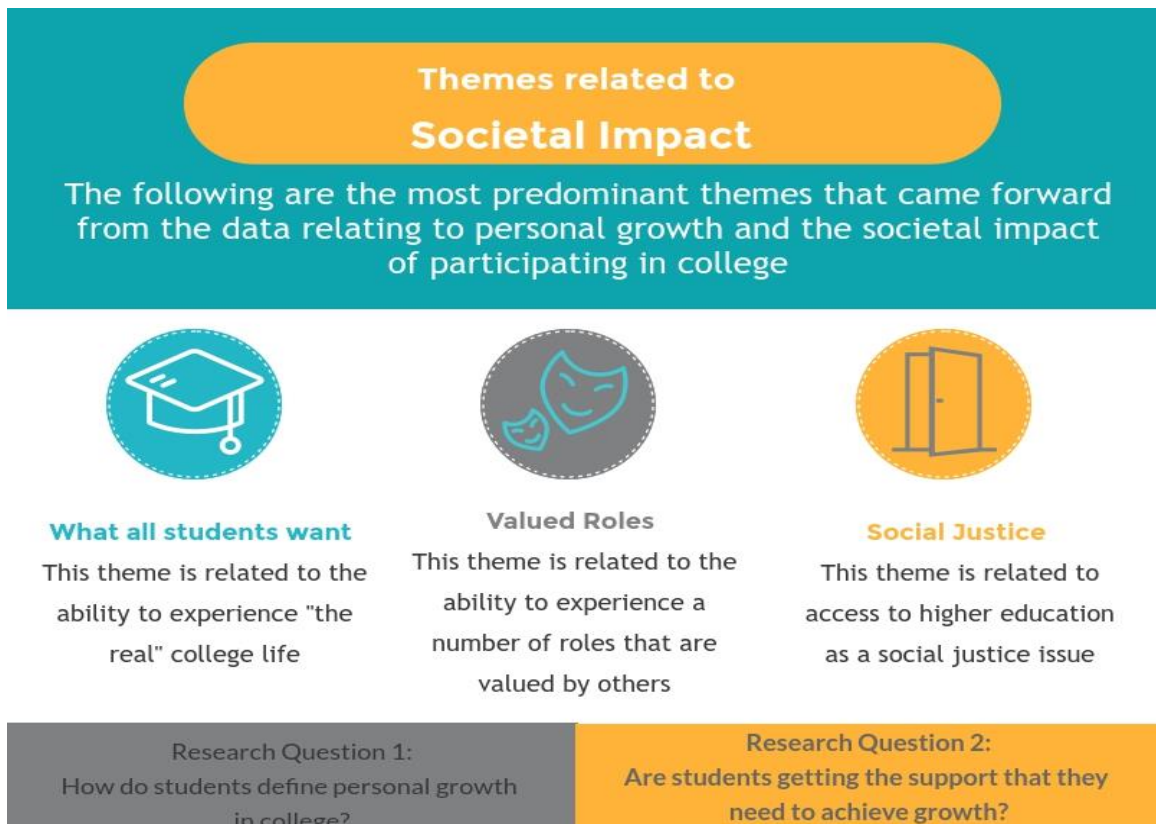


Figure 14. Themes (Partial Graphic)- Societal Impact

Theme 1 (College as a Path to What all Students Want)



I believe that when looking at our data regarding this theme, that it is informative to provide some context about what college students have universally identified

as important outcomes. There are a number of quantitative studies and/or surveys that speak to what students want out of their college experience. *The American Freshman: National Norms for Fall 2002* is a national survey that was conducted by the American Council on Education and the University of California at Los Angeles Higher Education Institute. More than 280,000 students responded to the survey, and identified the following as their top 5 reasons for coming to college: 1) to learn more about things that interest me, 2) to get training for a specific career, 3) to be able to get a better job, 4) to be able to make more money, and 5) to gain a general education and appreciating of ideas (Young, 2003, p.5).

In Bank, Biddle and Slavings (1992) study on student expectations and persistence, students reported 5 “hopes” that they had related to college, which are, in order of importance: social hopes (making friends, dating, compatible roommates, relationships with family and friends), academic hopes (pursuing specific courses of study, achieving career goals, having study time, getting help from faculty and getting good grades), personal hopes (personal growth, having leisure time, being independent, having privacy, improving physical fitness, partying and avoiding excessive partying) positional hopes (joining a fraternity/sorority, getting elected for student government/athletics, participating in club or activity), and financial hopes (having enough money to make it through the year, find a job that pays enough to stay in school) (p.326-327).

In 2002, the Association of American Colleges and Universities (AAC&U) commissioned a qualitative study that included student focus groups in different regions of the country. In Humphreys and Davenport's (2005) report, students ranked "what really matters" to them in 3 tiers, with top outcomes including maturity and knowledge of how to succeed on one's own, time management, strong work habits, self discipline, teamwork and getting along with people different from yourself. The next tier included business skills and specific expertise, critical thinking, strong writing and speaking, strong problem solving and analytical thinking, exposure to business world, and leadership skills. The third tier included values, principles and ethics, tolerance and respect of people from other backgrounds, computer competency, expanded cultural and global awareness, and appreciation of role as citizen (Humphreys & Davenport, 2005, p.7).

Data Analysis

Students telling us that they wish to be included in all aspects of college life like WALTER matter of fact as he describes a feeling of belonging and making us feel like we are at the club under the lights thumping base

**I would learn more German,
cook, bake
look at music videos,
Germany based music artists
I used to DJ at clubs/bars,
just take another whirl with that
people liked the music,
I like playing
hard style,
jump style,
trap
and
I like to play oldies
I djed
at the hookah bar,**

This is one of my favorite passages because it is so descriptive- I can see myself there, at the bar, along with other students- experiencing a college night like any other.

beneath our feet
as he spins us through
another night

Struck by MINNIE and MARC's
lists

their claiming of spaces
their belonging
not thinking twice
about access to all
that their campus
and community has
to offer

One after the other
students sharing
the same goals
desires

fears
as matriculating peers
and national survey reports
Banks, Biddle
and Slavings (2002)

framing
of hopes
resonating with me
as researcher
administrator
advocate and ally
most importantly
in support of each student's
right to choose
how to spend their days
their time
their resources
to decide
what being in college
and being a student
means to them

**the bar guy
he liked when I djed,
he liked pumping with it
and just having the right music
everybody was happy
when I was there (WALTER)**

**When I'm at UNCG
I like to go to Bojangles on campus
In the EUC and the library too
I like to go to Starbuck's**

**Target
Friendly center
(MINNIE)**

**College is,
it's like very amazing
to meet new people
learn new things and
getting a good job
and like helping
my family too (MARC)**

**I go to the rec center
lifting weights,
running on the track
I like to go downtown
go to events, like concert events
I know what's going on because
one of my teachers tells the whole
class that there's events going on
downtown
I go on the internet
I also go to the EUC talking to the
person who works at the front of the
desk
I choose these things- me (MARC)**

It is always amazing to see these lists open up and expand once students begin attending and exercising their freedom to try new things. We generally see very limited lists of activities when students apply, often based in segregated activities like Special Olympics. We used to try and keep our own running list of student connections once they started getting connected here- but now there are too many to count.

**Getting a degree
an apartment
a car
paying my own bills**
MARC's goals
and "personal hopes"
for life after 4 years
mirroring those
in the AAC&U report
the importance of living
on one's own
excited about college
and all it has to offer
echoing his peers
surveyed by
council on education
interested in learning
and good paying jobs

TORRES speaking of tradition
not captured as strongly
in the literature perhaps
but important nonetheless
particularly for those
whose roles have been limited
by society's expectations
RACHEL hoping to do the same
**I will be at UNCG
like my sister and my mother
and other staff who have
gone to UNCG**
PUDDIN wanting
the college experience
that her cousins are having
GOOD GUY and other students
wishing for a slice
of real college life

**You know I have family went to
UNCG,
my aunt in the eighties
my sister-in-law in 2005
I've been to campus a long, long
time ago (TORRES)**

We also see the opposite trend, as students who have been overscheduled in high school begin to experience the freedom of just "hanging out." Again, a common experience for college students- but one that parents of our students have a hard time with because they see it as regression- we have to advocate fiercely sometimes to support students and their right to "choose to chill."

**I would like to live in a dorm
with other people
and see how it feels
to be on a college campus
with friends
and people that are
nice to me (GOOD GUY)**

I was interested to see this theme of "kindness" come out of the data, of students wanting to have access to people who are nice to them. Bullying is something that many of the students that we work with talk about from their high school experiences, college seems to be a time that they can start fresh and rebuild their confidence in who they are. This is likely true for many of their peers as well.

JASON stressing importance
of growing as college student
offering formula
to academic success
“Academic hopes”
for any and all
managing time
taking notes
making time to study
going to the library
turning in assignments
making good grades
sleeping well
graduating
Goals shared
by every student interviewed

DOLPHIN expressing pleasure
with participation in classes
having access to specific courses
that help her narrow down
career
possibilities
students engaging in all parts
of college life
in and out of class
clubs and activities
TORRES and MARC
describing student life
fully engaged
reflecting how college
expands horizons
for all students
social and positional hopes
in full swing

Students clearly expressing

**I meet new people
in UNCG classes
and peer companions
peace and conflict studies
African American studies
People with disabilities in
American Society
(DOLPHIN)**

**I have quite a few
friends
in the program
and outside
of the program
both
we like to go to
different places
and stuff
go to fall events
and sporting events
and workout events
and stuff around the campus
(TORRES)**

**I'm in catholic club,
meeting new people
I like it a lot
Im connected to soccer events
I am into anime
my other roommate when I was a
freshman and he was a sophomore,
he showed me, I mean he told me
that there was an anime club
I liked it
I go to the rec center
lifting weights,
running on the track (MARC)**

Dolphin's list of classes is a great representation of her discovery journey in college- she used every class that she took to help her fine tune her interests, helping her move from an initial interest in photography to her desire to do counseling with children with disabilities- her use of college in line with what all the “reports” have to say.

multiple reasons for coming
to college
broad
and universal
In line with peers
ANNABELLE's personal hopes
I want to learn more skills.
I want to learn
how to pay the rent.
I want to learn
how to be more successful..
wants common to many
If the surveys are getting it right

For GOOD GUY,
college courses
mean a good paying job
and living on his own
RACHEL, JASON and JOE
all wanting to major at UNCG
wanting to take the SAT
wanting to enroll for a degree
same academic
and positional hopes
as peers
RACHEL going further to say
I want to study drama and music
looking forward
to being around other students
who can sing and act
JASON working through fears
It made me nervous
to take a class
with college students
who were not in my program
but i am glad that I took it
I know that I will work
with different people

My roommate
he introduced me
to students in other departments
they're really nice
I usually watch them play...
i usually watch them at their home
game
such as softball, volleyball, I
when they're heading to class
hang out
with an old friend
talk and chat
passing midterm
exams and finals
proud of
passing them
(JASON)

I am living
in spartan village,
I picked it
I like it a lot,
its very nice
roommates,
not so well
its cause the one
next to me
is making a lot
of music
I was talking
to someone
to help me with my problems,
living in spartan village
Its helpful
but if I could change anything
I would not like the walls
to be very thin
because you can hear every
conversation (MARC)

The co-writing process was an interesting one. Students often wanted to delete information that they felt did not show them in a positive light, or that they felt no longer applied to them. Reminders that we want to get a full picture of successes and areas of struggle in college were helpful, but some students, like Minnie, were not able to tolerate that conflict within their poems, and ultimately, it was their decision to subtract, add, or change. This does not diminish the impact of those poems, but it is something to think about for future endeavors with poetic analysis.

when I have my own business

ANNABELLE expressing a universal worry when she says **I am afraid of leaving the house with my parents alone without me**

a concern by no means particular to disability
MARC demonstrating the tensions that come with inclusion stresses that all college roommates experience supports needed for success with college living foreshadowing testimonials about difficulties common barriers to experiencing college life like their peers

PUDDIN expressing similar struggles with relationships what it feels like to be outsider dismissed Not welcomed frustrated because she sees college as a chance **to change about life be normal like other people** haunting words that speak to her experiences as other as unruly

My roommates the two of them, they good, one of them she just weird sometimes, they drink but they drink on their time, they don't party they just sit down and drink and talk and stuff comfortable as long as they not bothering me the only thing I like is everybody stay to themselves I got them cause I was living downstairs but then like it was the other roommates... they like to party and stuff I just told the people in the office to change me and then I had to pay like 200 Im gonna stay there its kind of hard to meet friends well back at home I do... but here I be trying to like, find friends but they be acting stuck up some of the people that's outside of BA and inside BA see they got they own crew, they don't want nobody else tried hanging out I know I had hanged out with a freshman I hanged out with her a couple times, but I don't know, she just be staying busy (PUDDIN)

Puddin speaks of wanting comfortable roommate relationships- a desire common to many college students. She also speaks clearly to her yearning to belong, to have her own network of friends as she sees other students having.

JASON describing conflict
Born of opportunity
the opportunity to live
on his own
with peers
learning
to navigate
to enlist support
and direct the outcomes
in his life

Academic life
also a clear goal
for most students
**going to school
and learning new classes
and getting good grades
is important to me**
WALTER saying
I take school very seriously
JASON affirming
that the school year
**felt good
getting good grades
I'm learning**
says MARC
**I'm Learning
and that is important to me**
PUDDIN experiencing success
early on
**When I first came,
I joined the UNCG
neo-black society,
gospel choir,
and I really love it**

**Rights stepped on
One time last year
two other guys
that lived
in the other
apartment
they tried to get me
to go to some club,
and I said no,
cause
I just didn't want to
and I felt
uncomfortable
another student
he got mad at me
and said shut up
in front of my face
I was a little scared
about saying
something
talked to the instructors
they gave me some advice and tips
Got resolved (JASON)**

**After I graduate
I might concentrate
on working for pay
its a good place
I want to stay in
Greensboro
for a little more,
like for a few more years,
Then go back to Durham,
four years to be exact i guess
maybe go to grad school
grad school back in Durham
get my own apartment,
keep my work
maybe one day become a master
auto mechanic (GOOD GUY)**

We often have to advocate with students to be able to experience real life consequences as parents have a tendency to swoop in and try to rescue their student from experiencing stress. We see these opportunities to experience things like their peers as some of the best ways to awaken and move to action. Understanding this has also prompted us to be more purposeful in how we support students in communicating that need/desire to their families as adults.

accessing what all students want
also means identifying
post graduation goals
like their peers
MARC getting specific
**I want to live in LA
by myself
in an apartment,
go out with my friends,
have a gym membership,
belong to a movie
and a bowling group,
see music shows,
have a girlfriend,
volunteer with kids
and have a mastiff to walk
and keep me company**
GOOD GUY working through
his post graduate plans
as any college student must
like degree seeking peers
Including
anxiety with what to expect
doubts concerns
MARC sharing his frustration
with institutional barriers
that limit his access
to what students want
Playing NCAA sports
Earning a degree
Access to more classes
Joining a fraternity
barriers present for all
for students without
matriculating status
pointing us to work
that needs to be done
so that all students can feel

**I wish I played
for the team for UNCG
Soccer
the program, it's really tough
Getting a degree
is a barrier
I would change that
something that is getting in the way
is that normally i want to take
classes that i want to take,
sometimes, right now for this
semester, I have short classes,
but I want to take a couple...
More choice
business and french
those are the main ones
I want to be in a fraternity
Like my buddy (MARC)**

A significant academic barrier is the inability to get a degree. This was a goal for the majority of the students... I have seen many struggle with how to answer the question, "what's your major?"-a frustrating question in the way that it others... this speaks to a larger need for exploring how PSE programs like ours can be valued and deemed "worthy" of bestowing degrees...

**One of my goals used to be to
graduate from the program
But now I have
I am a UNCG alumnus
I am very proud of that
(MINNIE)**

as fulfilled
as MINNIE

Theme 2 (College as a Path to Valued Roles)



Highlighting the importance of role identification for the students in this study is a reflection of what Wolf Wolfensberger calls social role valorization, defined by him as

The application of empirical knowledge to the shaping of the current or potential social roles of a party (i.e., person, group or class)-- primarily by means of enhancement of the party's competencies & image-- so that these are, as much as possible, positively valued in the eyes of the perceivers (Wolfensberger & Thomas, 2005m cited in Osburn, 2006).

Students claim a variety of roles that they read as valuable in their college community. This "enhancement of their own image" is a first step in SRV, which as Osborn 2006 says is a "response to the historically universal phenomenon of devaluation, especially societal devaluation" (p.4). I would argue that as their peers, faculty and university staff see students with ID claiming the very same roles that other college students inhabit, they are more likely to take the next step, where they see them (students with ID) as competent adults. You will see that this section of the analysis is short and sweet. Students were overwhelmingly content with the roles that they claimed, and they were diverse and meaningful in number. I think that a next step in research would be to explore perceptions by the community, to see if the increase and diversification of roles impacts how students with ID are perceived and valued.

Data Analysis

Students
articulating
identifying with a myriad of roles
related to their lives in college
in addition to his identity as
a bowling coach
and a helper for kids
JASON would like
to be a boyfriend
WALTER claims a number of roles:
UNCG student
club lacrosse player
goalie/d-man for UNCG
hockey coach/mentor,
and party DJ
future desired roles include
pro lacrosse player
club disc jockey,
and Australian Football
league player
TPAB recites a similar list
of valued roles
Important roles
ANNABELLE emphasizing
the importance of family roles
then
college roles
roommate
peacemaker
problem-solver
student and
graduate
value that comes
from social
affirmation
making it likely
as wolf would say

Being a sophomore

**A son, a friend
friendship**

**I give advice
to people who need it,
especially for
other people that
have autism
and I know how to
control it better
now that I'm older
learning to follow
before leading,
I learned that
you have to follow
before you can lead
to certain people
I could be
a leader (TPAB)**

**Being a daughter
to my family
and being an aunt
in my family**

to my niece and my nephew.

**Even though they get on my nerves
half of the time.**

**I love them for who they are
I'm a granddaughter to my mom's
dad..**

and to some of my aunts and them

I am a good peacemaker

Sometimes not all of the time.

A student.

**I want to be a graduate
(ANNABELLE)**

It would be interesting to compare roles before and after students come to college. Even for those students who are very involved, I wonder at the level of value that they have when oftentimes they are still seen as incompetent... if that is the case, what does that mean about SRV? The "forever child" comes to mind-even though as adults they may be highly involved in their communities, with "special" activities and such, are the roles that they inhabit changing the way that society values people with ID?

that she will
be able to
“experience the good
things in life (Osburn, 1998)

DOLPHIN
giving a telling example
of SRV
speaking directly
to her enhanced image
bolstered by
being seen
respected
for who she is
helping roles
essential part of feeling
competent
important
of value
JASON saying as much
MARC expressing
similar satisfaction

Majority of students
with similar satisfaction
receiving support that they need
to acquire roles
important
to each
challenging the
campus community
to see
with new eyes
and appreciate
their worth
value
that has

**I feel respected
when people see me
for who I am
some girls can be a tomboy
I feel respected
because I help out
I help with the community
I didn't used to be in front of people
but now
I get in front of people
because I had a chance
I had a chance
to help (DOLPHIN)**

**Roles
Role model
a helper
Son
Important role
a student
Important role
friend
a buddy
Feel good about that (JASON)**

**a student,
friend,
son,
roommate,
brother,
club member,
peer.
Happy
with roles
and proud of them (MARC)**

The interview question about social roles was one of the hardest for students to answer. I had to break it down and give examples of roles before they were able to start identifying any for themselves... once they got going, there generally fine. I think that this speaks to how infrequently they are asked to think of themselves in different spaces of value.

always
been
there

Theme 3 (College as a Path to Social Justice/Access)



Social justice is conceptualized here as equitable access to systems, institutions, resources, and/or experiences that have historically been unavailable to bodies that do not fit the “white, able-bodied, heterosexual, Christian and male” criteria traditionally privileged by the powers that be in the US- which in this case speaks specifically to higher education, as it has not be available to students with ID. Students involved in this research have articulated “hopes” that reflect Wehman and Yasuda’s (2005) description of higher education as “the ultimate educational experience and the way to attain greater income, improve the options in one’s life, achieve status, make more friends, and promote lifelong networks that allow for individual empowerment and personal capacity”(p.3).

Given that we are talking about access to higher education, it is also important to speak here about pedagogy... and beyond. Although Universal Design can be powerful, if educators do not challenge core beliefs about competency, and whether students with ID “should” be included in college classrooms, strategies will be for naught. This is what makes hooks concept of engaged pedagogy so significant for me, in contrast to inclusive pedagogy. I view Inclusive pedagogy as an external process, it is about utilizing a myriad of techniques, strategies and approaches to connect with a diverse group of learners. Engaged pedagogy requires the educator to look within, to be reflexive

and vulnerable, even as they invite the student to do the same. All life experiences and perspectives are seen as valuable in an engaged classroom.

Data Analysis

Students sharing feelings about access to higher ed and what it takes to experience be included in college life struggles with coursework and teaching that is not designed to engage diverse body/minds

Data showing that students want more access to degree track courses needing a variety of accommodations to be successful acknowledging some elements of university culture that limit and try to protect

We live in a culture where not everyone is accepting of everyone

says JOE struggling with how he is seen perceived understood by those who don't won't know

I would like to be in a school that understands how I learn. I have been attending UNCG and have been struggling with coursework (TPAB)

A right I can't exercise? letting kids with disabilities if they're talented enough, try out for athletics pretty much anything that is forbidden...

like if I couldn't do pep band, I would take offense to that like if I told them I have autism in this program, and they say oh we can't let you play because of that, I would take offense-instead of actually going out to try out for it... (TPAB)

I guess from who I am they see that my cerebral palsy and stuff they see that I mean, they treat us differently because they they see who I am and then automatically they assume that I'm gonna act a certain way.

Understanding the magnitude of pedagogical transformation that is required to see students with ID consistently and widely embraced in college classrooms makes this seem daunting. There is a great need for research on praxis in this area.

TBAB discussing frustration
With access to athletics
TORRES in agreement
**We have problems
everyday
with people
that have disabilities
and also
in the LGBTQ
community**
always with an eye
to intersectionality
**they can't get jobs
go to schools
and participate in groups
that they would enjoy
because apart of them
is not the same as
everyone else**

Going on to argue
the importance of awareness
in tearing down attitudinal barriers
TORRES explaining
his involvement
in advocacy efforts
frisbee
an unlikely place
to make a point
about social justice
but in TORRES' framing
one nonetheless
Before setting up his critical
understanding of taking action
TORRES sharing pride
in participation in advocacy/
photography program
with other community members
who are advocating

**I guess that's probably
because they don't know
if they don't have
they wouldn't know
But I think that's
just cause they
don't know.
that's what a lot
of my friends
have told me
(that don't have
disabilities)
they don't really
know what it is.
So they would
know what it is
More equality
I guess
(JOE)**

The comment about Frisbee is deceptively significant. In order to be a member of the "anyone" who can just show and play, our students and allies have had to break down any number of walls just to get to the field. Once they get to the field, our students will need an understanding of the unspoken rules around cooperative play. Once there, one hopes that other students will make space without preconceptions about ability. Whenever I see things like this happening without fanfare on campus, I am moved by the different layers of meaning.

**sometimes play ultimate frisbee,
you know ultimate frisbee
anyone can just show up on
campus and play it,
there's no sweat about playing
and I do the sociology stuff,
you know protesting for different
things.
I actually started a movement,
its online and a lot of UNCG
students are connected,
where race is a social construct,
cause we're learning from different
countries that have actually taken
race out of their government,
I was learning about how France
took race out of their government,
so we're a movement to try to do
that in america (TORRES)**

for a more welcoming and inclusive community
Another example of action
For justice

TBAB thinking through reception
or lack of reception from faculty
his own responsibility in moving beyond
in the face of “educational practices in higher education that have created significant barriers to access retention and graduation for many students, particularly students with disabilities”
(Pliner & Johnson, 2010, 106).

then ironically speaking of barriers that peers with ID may meet as well as his own discomfort complicity in perpetuating bias
one example of dissonance that many students experience the push and pull between not wanting to claim

**there's always that one faculty, there's always that one that gives you problems
I would talk to them and explain to them that you know,
I am not really agreeing to how you're doing this
and if they listen then you know everything's back to normal
and if they don't, then I just mute them out
mute them out like my...
I feel like I have any freedom to address it the right way, exactly cause you know, you got some folks out here that you don't address it the right way (TPAB)**

**Some barriers truthfully there are a few people that whenever I hit somebody up, they're always quick to try and jump in as well and being that you know the kind of personality that they have,
I be kind of afraid to have them jump along in with these folks. Certain people's personalities I'm afraid won't mix
So I have to be kind of cautious about that
I hate throwing them under the but That's true (TPAB)**

Understanding the magnitude of pedagogical transformation that is required to see students with ID consistently and widely embraced in college classrooms makes this seem daunting. There is a great need for research on praxis in this area.

an identity that so many
see as “less than”
and relating to folks
who share ways of knowing
lived experiences
representing the complicated
nature
of access
Students speaking up
about rights
TORRES
Intertwining thoughts about rights
and access to education
important point
that he is thinking through
accessible formatting
for higher education
“I am a big advocate for equality”
he says
**for equality specifically,
you know disability rights
is equality
all of its equality**
unknowingly echoing
Slee (2001)
claiming that “inclusion
is an aspiration for a
Democratic education and
as such
the project of inclusion
addresses the experiences
of ALL students at a school”
(p.168).
The importance of making
space for unruliness
for bodies and minds
that are not white,
able-bodied, heterosexual,

**I think everyone has the right to be
protected
you have the HIPAA law and the
FERPA law for education
I exercise a lot of rights,
the freedom of spirituality-
the freedom to believe in what you
want to believe
what it all comes down to
is to exercise that right.
some people don't know about the
rights that you have
A lot of people think just because
I'm black you know,
I just don't have any rights
that's not true
the right to be free from cruel and
unfair punishment
Education,
now they have more on-line
education courses
its more accessible these days
(TORRES)**

**I have the right to do anything I
want to do,
like have friends,
be independent,
not have people tell me you can't do
this, you can't do that.
I can do whatever I want to (GOOD
GUY)**

**Folks treat me
very nicely
fairly
respectful
listening to me
like I'm important
I feel like I'm treated pretty good,
they respect who I am**

Christian, and male”
(Pliner & Johnson, 106).

Students demonstrating
that they know their rights
feel confident
in accessing them
speaking up
when violated

Ultimately,
students acknowledging their
right to be in college
ANNABELLE, MINNIE, JASON
clearly expressing
how they believe
college has changed their lives
ANNABELLE,
answering questions about
access
with
“Not really anything I can’t do
Not really any place I can’t go”
MINNIE unequivocal
in her understanding of rights
and definition of respect
JASON affirming how practice
directing his own life
on campus
has been transformative

Finally,
JOE giving us his motto
Millennial anthem
connecting him to the broader
expanse of contemporary,
college aged students
Everyday keep your head up

I have the right to go to college.

I have the right to go places.

I have the right to vote

That’s all I can say.

I can vote.

I can do what I want.

Have everything

I need (ANNABELLE)

I have rights

**I have the right to
go to school**

College

**I have the right to be
a college student**

**I have the right to be
anything I want to be
I feel like**

I am treated fairly

**When I am respected
by other people**

Other people

who are not mean

Who look me in the eye

**Who are friendly and who listen to
me MINNIE)**

My role has allowed me to observe transformations like this. JASON was extremely unsure of himself in his first year, and rarely trusted his own knowledge. As the years have gone by, I have watched his confidence and his faith in himself grow. Having the opportunity to practice all of the skills that he listed has been a significant part of that growth, and one of the reasons that we advocate so strongly for students to have the freedom to live and learn on their own- like their peers. Being away from home and breaking old patterns of caregiving can be tricky for any student.

**no matter what, even if it's on
your worst day
because life always gets better,
life is not just about
going to college and
getting a job,
there's always more to explore
in life that you haven't gotten
your hands on
so never give up**
his words launching us into
a final discussion
on college's role
in our student's lives

**I feel like college has changed my
life
like going to classes, day to day,
learning something new, textbooks,
class assignments,
looking it up on canvas
using the syllabus
Making life better
keeping on track with my financials
finding the buildings, getting
around with the maps
keeping me alert about things
happening on campus
Making life better (JASON)**

For Walter, not being able to access study abroad was an extremely frustrating barrier. We have made inroads as a program in his time here, and this may well be an option for other students, but, his journey to critical consciousness was undoubtedly less impactful without the opportunity to fully explore what he considers to be an integral part of his identity. This is an example of the many layers of access, and that students are telling us that they want to keep pushing... - -

**College
I want to find out what the future
was for me
try to figure out what you want to
do after
decisions and stuff...
taking a foreign language
so I can go over there for awhile
study abroad
I haven't been able to
but I wish I had
Deustch ist gut
Deustch
ist
gut (WALTER)**

CHAPTER VIII

CONCLUSION

New ideas will indeed be necessary to complete the social revolution for people with disabilities that began in the 20th century. Students who benefit from a postsecondary education can look forward to a future (research indicates that even taking one course in a postsecondary education setting leads to better outcomes) that refutes the negative statistics that comprise the current reality. Data reveal that 90% of adults with intellectual disabilities were not employed; fewer than 15% participated in postsecondary education; and over 700,000 people with intellectual disabilities lived with parents aged 60 or over (Grigal & Hart, 2010, p. xi).

Significance of this Research

Yes, new ideas will indeed be essential if folks with disabilities are to be included in a social revolution that leads to access to higher education. I am most recently reminded of this after looking through the resource materials and unity principles for the local, national and global Women's Marches that occurred in January of this year. Even for a collective movement such as this, that founds itself in intersectionality, disability is almost invisible. In fact, not one disability related organization is represented by the authors of the documents, disabled voices seem to be missing and or silent. That is why research like this is so important. To shed light on the ways in which "unruly," disabled body/minds are discounted and presumed to be incapable and/or unimportant. Unrestricting the

imagination in a way that challenges thinking which marginalizes these students in terms of postsecondary options is long overdue. We are in need of new ideas that push on institutional bias that limits, restricts and discounts.

Broadening the imagination as MacIntyre envisions, and viewing students with ID as capable adults, should make answering the question “why college” seem obvious. National studies like *Education Pays* (2013) tell us that college degrees and experience result in more employment and better working conditions, as well as better quality of life (p.10). Students with ID have historically been shut out of these opportunities, have been excluded from educational experiences that have resulted in such positive outcomes for their peers (Grigal et al., 2011; Hart et al, 2004). The students in our research seem to resonate with data from studies like this, communicating that they want the very same things out of their college experiences. In the broadest sense, this research is significant because it centers student voice in the answering of the question.

More specifically, this research is important because 1) it informs the program in which the students are enrolled and adds to existing scholarship about postsecondary education for students with ID, 2) it challenges traditional approaches to research -offering creative, emancipatory alternatives, and 3) it acts as a call to action for the higher education community regarding inclusion of students who are deemed unruly, like those with ID. I think that it is also significant in its framing of praxis in three discrete areas of focus, practice for the person, practice for educators, and practice for the community.

Programmatic Changes

Since the 1970's, the majority of postsecondary programming for students with ID has been community based, with a focus on independent living skills, employment and recreation. Programming that includes "academic and social activities" began to evolve in the 80's and since the Reauthorization Act of 2008, we have seen a proliferation of well more than 200 programs that seek to provide high school students with the opportunity to "receive instruction in settings similar to those experienced by their same-age peers without disabilities" and center inclusion in higher education as their foundational premise (Grigal & Hart, 2010, p.5).

Despite these changes, and those at the secondary level designed to improve transition outcomes, students with ID typically graduate with alternative diplomas, few chances for meaningful, supported postsecondary activity, and often have to endure long waiting lists just to get support from human service providers (p.5). With approximately 250 postsecondary programs now in existence across the nation, research that explores how programs are able (or not able) to ameliorate these issues takes on a new importance (Grigal & Hart, 2010; Grigal, Hart & Weir, 2012; Grigal, et al., 2013).

This study has the potential to act as a guidepost for future research, both in the area of development specific to this program, as well as broader PSE programming. In regards to the program here at UNCG, it represents the first stage of what will be an ongoing community engaged research process designed

to ensure that student desires and needs shape the program. Data from this initial stage points to a need for further development/exploration of the following:

- Creation of or affiliation with a recognized credential
- Efficacy of career supports in college setting
- Campus culture and impact on access/inclusion
- PSE programs as visionary pragmatism in the three areas, practice for the person, practice for educators and practice for the community.

These recommendations will be offered to the research circle for review, as action steps for the next stage of research are determined.

Although these recommendations for research are specific to our program, they also have bearing on the national postsecondary conversation. Given existing literature related to employment outcomes, access/inclusion and campus culture, I think that our greatest strength is in our ability to inform scholarship around credential development and visionary pragmatism. In the recognition of the wide variety of structures and approaches for the 250 PSE programs in the US, there is a national push to address accreditation and credentialing (Shanley, Weir & Grigal, 2014).

As one of a handful of 4 year programs nationally, we are in a unique position to provide input about the impact of that timeframe on student outcomes, particularly in the areas of critical consciousness and discovery/career development, of which self-determination is an essential element. There is already a body of research that explores the link between self-determination and positive adult outcomes for students with ID (Wehmeyer & Palmer, 2003;

Wehmeyer and Schwartz, 1997; Wehmeyer and Schwartz, 1998; Ohtake and Wehmeyer, p.170; Shogren, et al, 2015). I would argue that our research is significant in that it explores the impact of having a full four years to move through the stages of both and that it would be valuable to engage in future research about such. It is also significant that as Wehmeyer (2016) argues, research has “consistently found that explicit instruction to promote self-determination is limited” (Wehmeyer, 2016, n.p.)- postsecondary programs like ours are prime vehicles for studying self-determination in a pedagogical sense.

Self-determination also serves as a link to the idea of visionary pragmatism related to day to day volition and intent to action, or what I am referring to as practice for the person. Patricia Hill Collins describes visionary pragmatism as the intersection between theory and the practical, day to day (Collins, 1996). Postsecondary programs have the potential to operate at this intersectional point, when they use theory to inform the ways in which they support everyday student agency. Federal guidelines require that programs incorporate person centered planning into their program practice. If this student-centered planning incorporates elements of Wehmeyer’s principles of self-determination, I believe that students can get a clearer idea of how they are or are not moving through stages of critical consciousness, an awareness, as Carlson et al. (1996) argues, that is an essential building block for agency.

Another possibility for linking vision and daily practice is through transformation of pedagogy, or what I refer to as practice for educators. As

students with ID become more of a presence in college classrooms, and as they continue to demand opportunities to have their learning count towards degrees like their peers, educators will have to reevaluate their teaching practices. Practical UDL strategies in concert with a theoretical working through of concepts like engaged pedagogy, may well provide a possible blue print to a more inclusive pedagogy. I address this on a broader scale as I discuss access later in the chapter.

The final linking that I think is informed by this research, is practice for the community in the form of social role valorization (SRV). 'SRV is perhaps not as prominent today as it was during the time of its inception, but I think that it can still have a contemporary application within postsecondary education research. Students are experiencing roles that have not historically been available to them as they live, learn and play on college campuses. This is a crucial time to examine how these new roles are impacting perceptions of both students with ID and the community at large, connecting praxis with future research applications that can inform such change.

Research

Beyond the programmatic implications mentioned above, there are a number of ways that this research can be taken forward to expand ideas of research within the PSE community. One can easily find literature that highlights the voices of disability professionals regarding the importance of higher education for students with ID, but it is harder to find studies that center student

voice. Walmsley (2003) asserts that “recognition that people with learning difficulties are capable of insight into and analysis of their experiences is comparatively recent” (p. 40). This research is positioned to support such a statement and contribute to much needed scholarship and the base of knowledge around emancipatory methods that highlight perspectives of students with ID.

Wallerstein and Duran (2006) make an important point when they say that reviews of research literature generally focus on “empirically supported interventions” that value scientific evidence, and that such emphasis can “inadvertently delegitimize knowledge that comes from the local community” (p. 315). Future community engaged research efforts can challenge this empirical focus and give weight to the integration of “culturally supported” methods and interventions that challenge the privileging of one type of “scientific” methodology over others. They can also work to “equalize power relations based on knowledge” within community engaged teams (Wallerstein & Duran, 2006) as we did with the inclusion of student co-researchers and peer interviewers. The involvement of students in all stages of the research process connects to Walmsley’s reflection that unrestricting “imagination is the key to a more emancipatory approach both in the practice and in the research methodology” and that we as researchers need to put away stereotypes of “the powerful professional” so that we are truly “receptive to capacity” in all of its many forms (p.59).

Acknowledgment of the import of co-research and collective construction of knowledge pushes on ideas of “scientific validity” and claims that neutrality is essential for research to be of value. Community engaged research that is emancipatory has great potential for unrestricting our imagination around methodology and traditional roles in research. I think that there is a great need for others to engage in research that encourages processes where power is shared and knowledge is co-created and where “disabled academics and researchers are able to use their academic work to argue for social change” (Strand, 2003, p.12). Defining social change and how it is informed by research is a crucial next step in our process, as emancipatory research must be about more than just giving people opportunities to tell and analyze their stories, but also about opportunities to take control of the research process itself (French and Swain, 1997, p.28).

To effectively carry this out, it is be important to understand how to provide support in a way that does not compromise participant voice/engagement, but instead amplifies or illuminates feedback from co-researchers (Walmsley, 2003). It also requires an exploration of “means of expression beyond the conventional which most accurately conveys the perceptions and experiences of vulnerable people” (p. 41). As Strand (2003) asserts,

This may mean that professors and scholarly standards of proof must think instead of the need for concrete results presented in a form that is comprehensible to neighborhoods, organizations, politicians, agency personnel, and others who might make use of research findings. It requires that researchers demystify the language used in research reports

might also call for the use of innovative, creative methods of describing and reporting results that may not involve writing at all: video, art, community theatre, or quilting, for example. (Strand, et al, 2003, p. 1)

This is where Arts-based methodologies can come into play and my graphic guide in chapter 4 is a first step in this direction. As I was creating that chapter, I was forced to get clear about my understanding of concepts so that I could represent them visually. This process of “distillation” was very similar to my experience with poetic analysis. Both of these artistic methods required a simplification and concretization of language that works well for any audience member who does not respond to traditional reporting formats which often privilege inaccessible language. One of our circle members, in fact challenged me to push harder in this arena, to develop graphics that used no words at all; an exercise that is exciting to consider for future scholarship.

Another exciting area for future research is what Scheuer (2011) describes as art, music and poetry created by disabled artists which challenges “understanding about disability by “extending or changing the terms of the conversations that people are having about disability, the body, aesthetic theory, accessibility and communication” (p.159). Research methodologies that embrace different ways of embodying knowledge play an important role in expanding the ways that people can come to understand what people with disabilities have to say about society, their lives and needs. Scheuer (2011) goes on to say,

By creating new, startling, or nuanced metaphors and poetic images, disability poetry can begin to alter the “objects of emotion” that circulate in public discussions of disability. Disability theorists have noted that disabled bodies are often used as the vehicle of a metaphor, made to signify negativity, deviance, or pity (p.162).

Scheuer’s words bring to mind the word image described in the introduction that was made from all of the negative comments from disability professionals, an image that suffered from lack of input from people experiencing life with a disability, and who undoubtedly would have other ways to represent themselves.

The poetic analysis enacted in this research just scratches the surface of how poetry can provide a unique representation of the experiences of people with disabilities, specifically ID. By pushing the poetic method beyond found data poems that rely heavily on the lead researcher, who likely does not have an intellectual disability, students can take more ownership of the creative research process by using poetry to respond directly to research questions for instance, I believe that we can reach deeper understandings of what students want. In this way, the poetic method would be more likely to result in what Ferris (2006) describes as crip poetry or poetry that “seeks to explore and validate the lived experience of moving through the world of disability” and which “embodies a disability consciousness; [that] is informed by and contributes to disability culture” (p. 1).

Disability or crip poetry “centers the experience of disabled people; it shows “disabled people taking control of the gaze and articulating the terms” by which people view them (Ferris, 2006, p.1). It is exciting to think about how the

emphasis on self-definition, embodiment and the use of “alternative techniques and poetics” within this tradition might manifest themselves in the writing of students with ID on college campuses. The existence of such is described by Ferris (2006) as having the power of radical transformation,

a transformation in consciousness, not only the consciousness of the poet and the reader, but the potential to transform the world, to make the world in which we live roomier, not only more transparent and known, but to make more space in the imagination, and so in the culture, for the wide and startling variety of rich and fulfilling ways that real people live and love, work and play in this world (p. 1).

Ferris’ description reflects Carlson et als definition of critical consciousness, and illustrates how poetry itself can align with student desires to come to know themselves in a way that leads to action, and that also can lead to expression that is embodied and reflective of their “unruly” lived experiences. This is a rich and exciting area for future research, that I think as Ferris (2006) says, “finds value and strength within disability experience, not in spite of impairments, but because of and through them” (p. 2). I also think that it can deeply inform the national conversation about how access to college campuses impacts quality of life for students with ID.

Access to Higher Education/Social Justice

Access to higher education for students with ID involves a myriad of factors to consider including campus climate, instructional design and faculty attitudes, institutional barriers, family preparedness and support, and individual

motivation. Student participants in this research have specifically identified the following issues as significant regarding access here at UNCG,

- barriers to full access to college life (limited participation in degree track classes, ineligibility for NCAA sports, certificate vs. degree completion)
- Implications regarding inclusive pedagogy and UDL
- Barriers to college presented by family structures/expectations
- campus culture as it impacts access/inclusion

and I would argue that all of these issues could benefit from follow-up research.

Research that examines the willingness of faculty to ensure that their classes are accessible to students with ID is limited at best, and highlighting courses and faculty that make it work in contrast to those that don't (or won't) can inform local programming as well as the national PSE push for access. This push will require supports to faculty who are unfamiliar or inexperienced with UDL, to ensure that they have practical strategies for making their courses more accessible. There is also a great need to provide support to offices of disability services to build capacity, tools and approaches for supporting students with ID as well as offices of student success who may also need training or consultation as they provide academic supports to students with ID. These approaches to support are promising in that they focus on addressing things at an institutional level, rather than focusing on trying to "fix" students with ID.

Another area that students expressed frustration with, were barriers to playing college level sports. Eligibility for NCAA sports will require action at a

broader level, to challenge the institutional barriers that require matriculating status. A sea shift in the ways that students with ID are viewed as having a right to the college experience will be necessary to see some revising of those eligibility requirements. The same can be said for access to college degrees.

Ultimately, as students demand to be treated in the same ways as their college peers, pedagogy must change for academic access. Our students desire more access to a wider variety of coursework and inclusive, universally designed instruction that will help them be more successful. If students are to be fully included academically beyond just having opportunities to audit classes, pedagogical practices must be examined on all college campuses, including ours. It will be necessary to re-evaluate the ways in which college classes are taught, and how students and their knowledge are evaluated. Challenges to ways of knowing and who regulates such will require a critical lens through which to view pedagogy, curriculum and assessment.

As Paulo Freire frames it, critical pedagogy represents the “delicate balance” between social change and intellect, emphasizing the effort it requires to change the world, as much as it does with cultivating knowledge and analysis (Kincheloe, 2007, p. 21). Kincheloe (2007) describes it further in this way,

Critical pedagogy is interested in the margins of society, the experiences and needs of individuals faced with oppression and marginalization. It is not merely interested in the experiences and needs of students who came from the mythical center of the social order. Thus, critical teachers seek out individuals, voices, texts, and perspectives that had been previously excluded... Critical pedagogy, thus, amplifies the voices of those who have had to struggle to be heard (p.24).

The voices of students with ID have been all but invisible in college classrooms, and the need for critical pedagogy that “amplifies their voices”, as well as faculty who can “deploy multiple methods of producing knowledge of the world” (p.37), is seen by the students in our research as a key element to their success in higher education. Research in the area of pedagogy and praxis is needed to understand how educators can as bell hooks says, effectively “shape the way knowledge is produced and transmitted in the classroom” and teach in a manner that “transform(s) consciousness and creates an atmosphere of open expression” (Kincheloe, 2008, p.84).

Inquiry that employs arts-based methods has great potential for challenging propositional or “factual” modalities of knowing that have been historically privileged over those experiential, practical, and presentational modes that make up our lived experience (Page et al, p.580). Scholarship that examines how classrooms have become sites of such privileging, and can offer strategies for broadening knowledge production and using the arts to “reintegrate aesthetic experience into propositional knowing” could be significant means for ensuring access for students with ID.

In my experience, college faculty use UDL at different levels and with different rates of success, and it will take work to provide the support that faculty need to make substantive changes in their pedagogical practices. For a variety of reasons, I believe that taking the next step towards engaged pedagogy will be an even harder sell, because incorporating this approach is not prescriptive, it is

more demanding than other approaches and it is not easy to define. hooks describes engaged practice as that which involves educators in assessing their own well-being and promoting self-actualization so that they can empower students through their teaching (hooks, 1990).

The emotional connection is not one that educators are used to accessing and/or exploring as a part of their professional development, and I imagine that there could be some resistance for those who view teaching as a reflection of the banking method- a one way process where they, as the authority figure, simply transfer or deposit information (Freire, 1974). Even the most flexible of educators will likely need support as they attempt to move from hooks' theory to successful daily practice. Our students have an opportunity to help educators contextualize this as they become more involved in a wider expanse of college classrooms, and PSE programs have a responsibility to assist by offering strategies and support.

Engaged pedagogy is a practice of freedom, as hooks (1990) says, where students take responsibility for their choices, and where teachers share power by allowing themselves to be vulnerable. Both acts of courage create an environment where learning for all can thrive- a key component of any formula for access.

A Few Final Thoughts

As I bring this stage of our research to a close, there are a few things that are still at the forefront of my mind. I still find myself in a state of discomfort with

the tension between wanting to fully commit to the community engaged process and the fact that this is part of my individual doctoral research. I feel uncomfortable claiming this work as “mine.” I feel uncomfortable with the level of authority that I have had in formatting this presentation of research. That discomfort pushes me to get feedback from the research circle about next steps, who owns the research from here and how we want to present it to the community.

Secondly, I am anxious to see how this research will be met by the PSE field. I have watched folks at conferences flock to sessions about practical strategies and more traditional types of research, and have experienced less interest in non-traditional approaches. It is my hope that the voices of our students and the implications of what they have to say are taken seriously. In rereading each poem (see poems in their entirety in Appendix C), I am further reminded of the power of their words and the importance of ensuring that they are at the center of all that we do.

Thirdly, I am excited and thoughtful about my foray into the use of multimodal approaches, even though I feel like I have just scratched the surface. Using visuals and poetry helped me to crystallize my thoughts and make theoretical connections in different ways. The layering of analysis was instructive and the process of constructing the different components often sparked connections between the layers that I might not have made otherwise. I think that this experience points to possibilities for exploring how using a universally

designed approach to research can enrich analysis and deepen our understanding as researchers. Using visuals and poetry to translate both scholarship and results/analysis brought me to different place of knowing than I would have otherwise. I believe that, as UDL would assert, I have a better understanding of content, and that my learning in fact has been more effective, because I used multiple senses and modes of expression throughout the research process.

Finally, I am looking forward to taking next steps towards more engaged poetic inquiry, where participants respond to research questions through poetry, as I think we will see a richness in the data that we have not experienced as of yet. This will require workshops and instruction to research participants regarding poetic conventions and writing- a coming together of art, research and consciousness-building that is very exciting to me.

Limitations

As exciting as it is to think about ways that this research can spark other inquiry that may help broaden access for college students with ID , it is also important to address what may be seen as limitations of this approach. Patti Lather (1986) warns us to be cautious about the framing of research methods as “emancipatory” as they may contain “tacit forms of oppression” (p. 97). Her point is a good one. Even as we work to ensure that students are involved in all aspects of research, and are empowered to guide the process themselves, we must acknowledge that we are still operating within a flawed institutional system

that continues to dismiss and discount perspectives that are seen as “other.” “In an educational context,” Lather contends, “this oppressive dynamic of emancipatory action becomes profoundly dangerous, as its transmission-based pedagogies can work to disempower and marginalize in the name of justice and equality” (p. 97).

Another limitation to be considered is the time-consuming nature of community engaged research and the resources required to effectively conduct it. Knox, Mok and Parminter (2000) stress the issue of cost, saying,

funding bodies must acknowledge and support the additional time requirements of collaborative research, if there is, on their part, a true commitment to the participation of people with disabilities, beyond that of tokenism (p. 57).

The length of time that it takes to conduct this type of research has to be taken into consideration, particularly when one of its goals is program evaluation. Because results are not in “real time” it becomes difficult to fold feedback into program development in a meaningful way.

The concern about tokenism is also of particular concern to me. Inclusive research is a skilled activity that requires a careful examination of the power imbalances that can occur between researchers with and without disabilities, to avoid the danger of engaging in what Walmsley (2004) calls the “rhetoric of participation” (p.66). This goes beyond just “support,” which is how it is often framed (Williams, 1999 as cited in Walmsley, 2004, p. 66). To move beyond paying lip service to co-research it requires an understanding of research and

communication strategies that encourage rigorous involvement in the research process, and requires a commitment to avoid what Stalker(1998) describes as rubbish research.

This tendency to see qualitative/community engaged research as less rigorous and valid than quantitative, more empirically focused methods is yet another limitation. Wallerstein and Duran's (2006) discussion about how the privileging of empirical methods can deligitimize community based knowledge is significant. As a researcher, it is important to be aware that studies such as this may not speak to certain funders, legislative bodies and/or other administrative agencies that use research to support decision making.

Limitations aside, I would argue that there is still great value in the use of community engaged research that incorporates arts-based methods. Engaging students as co-researchers in creative ways that honor different styles of communication and different ways of knowing can only enrich and inform PSE scholarship. It is a hallmark, I think of what Grigal and Hart (2010) describe as "the successes and advances achieved in our society during the past thirty years in public attitudes, education, pedagogy, technology and medicine [that] have made this postsecondary innovation possible" (p.xi).

And so I choose to end as I began
with a poem
letting the spaces tell the story
as much as my words.
bringing it all together

feelings about the research
and what may come after
feeling responsible
under the weight
of justice
of just us
ready and willing to fight the fight
WITH other makers of knowledge
powerful collaborations
challenging those who say
I cannot become
they cannot become
we cannot become
we cannot
give in
give up
give out

feeling fearful
of sitting just at the surface
and missing
missing the truths
truths that swim through the depths
mocking me
from just below where the eye can see

feeling receptive
ready to listen and
get myself
out of the way

making room
for voices
life histories
testimonies
lived narratives of someone else's truth

feeling in position
clear about influence and intent
transparent in thought and word
connected to the bigger
PSE picture
breaking it down
to put it back together

feeling creative
flexible and fierce
using words like a canvas
painting thoughts into being
in partnership with
those ready to find a brush
of their own making

feeling pushed
running on a hamster wheel
worried
about how far
there is to go
working hard
almost getting it
almost

but
not
quite

feeling unsure
words not strong enough
ideas not meaningful enough
skills not skilled enough
struggling with
consistency
time
too academic?
not academic enough?
same old struggle

feeling content
somehow
to the degree that I can
belly full
with knowledge
not solely
of my own making
tools at the ready
guideposts in place
and waiting
for the next
getting ready
for change

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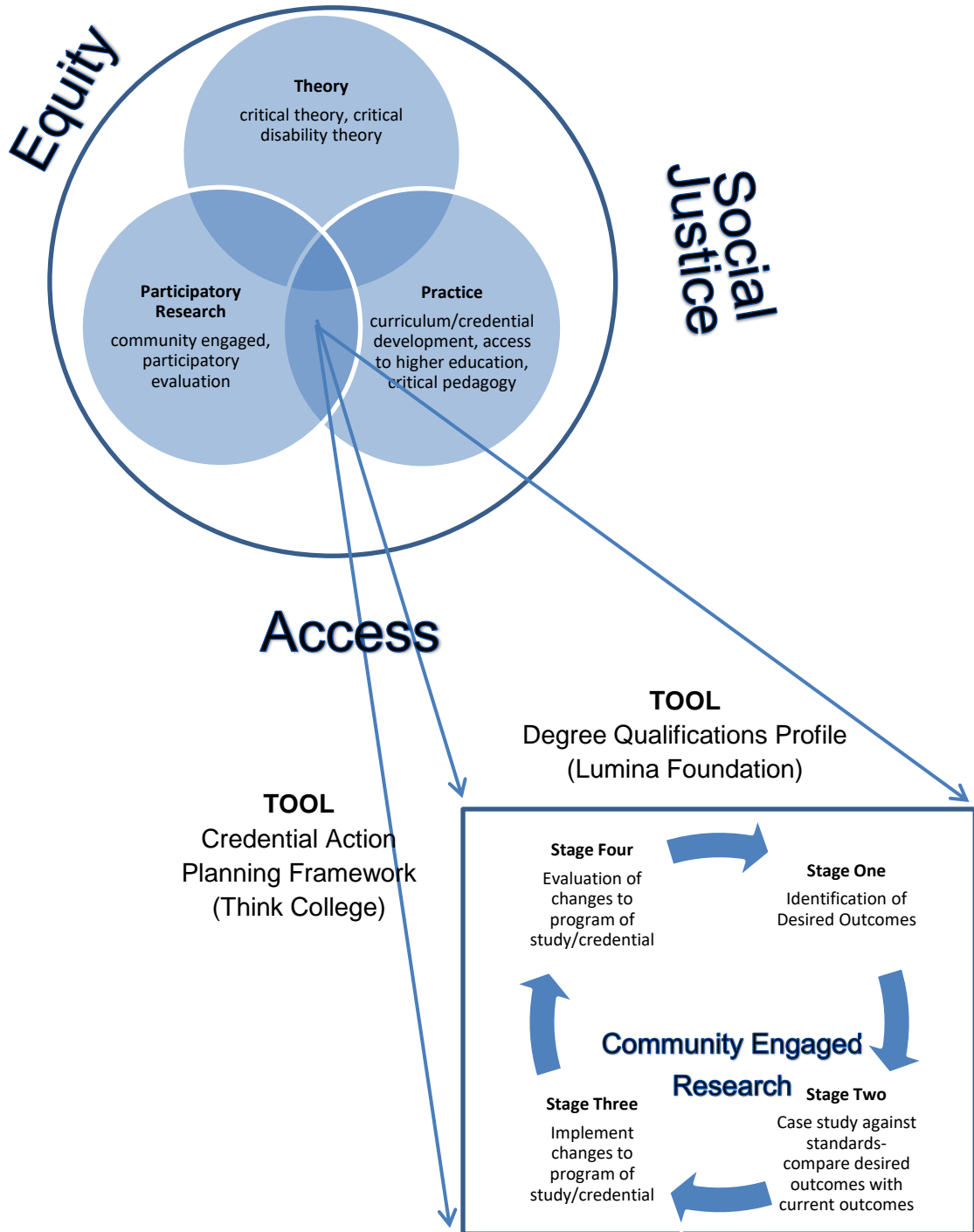
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APPENDIX A

CONCEPT MAP



APPENDIX B

MODIFIED INTERVIEW PROTOCOL

This protocol was modified for use by peer interviewers.

SAFETY

You told us that... fill in summary of information supplied in first interview related to safety.

Questions

Is that correct?

Do you feel safe in your current home and community?

At work?

Do you have the supports that you need to feel safe?

If yes, Can you tell me what they are like?

If no, where do you think you can get more support with this area?

Have you encountered any barriers? What has helped?

HEALTH

You told us that... fill in summary of information supplied in first interview related to health.

Questions

Is that correct?

Do you have the supports that you need to maintain a healthy lifestyle?

If yes, Can you tell me what they are like?

*If no, where do you think you can get more support with this area?
Have you encountered any barriers? What has helped?*

RIGHTS/TREATMENT/SECURITY

You told us that... fill in summary of information supplied in first interview related to rights, fair treatment and security.

Questions

Is that correct?

Do you have the supports that you need to understand your rights?

Do you have the supports that you need to address concerns about how you are being treated?

Do you have the supports that you need to get help if you are being abused, neglected or exploited?

If yes, Can you tell me what all of these supports are like?

If no, where do you think you can get more support with this area?

Have you encountered any barriers? What has helped?

CONFIDENTIALITY/ Right to privacy

You told us that... fill in summary of information supplied in first interview related to confidentiality and privacy.

Questions

Is that correct?

Do you have the supports that you need to understand confidentiality and how to manage the sharing of your personal information?

If yes, Can you tell me what they are like?

*If no, where do you think you can get more support with this area?
Do you feel like you are respected? Can you give me an example either way?*

Have you encountered any barriers? What has helped?

SUPPORTS

You told us that... fill in summary of information supplied in first interview related to paid and non-paid supports.

Questions

Is that correct?

Do you have the supports that you need to manage your services?

If yes, Can you tell me what they are like?

If no, where do you think you can get more support with this area?

Have you encountered any barriers? What has helped?

FRIENDS/COMMUNITY CONNECTIONS

You told us that... fill in summary of information supplied in first interview related to friends and relationships/community connections.

TRANSPORTATION

You told us that... fill in summary of information supplied in first interview related to transportation.

Questions (related to both topics)

Is that correct?

Do you have the supports that you need to access and participate in the campus and or community?

Do you have the supports that you need to have relationships with people in your community?

If yes, Can you tell me what they are like?

If no, where do you think you can get more support with this area?

Have you encountered any barriers? What has helped?

Have you encountered any barriers? What has helped?

LIVING SITUATION

You told us that... fill in summary of information supplied in first interview related to living situation.

Questions

Is that correct?

Do you have the supports that you need to live where you want to live?

If yes, Can you tell me what they are like?

If no, where do you think you can get more support with this area?

Have you encountered any barriers? What has helped?

CAREER

You told us that... fill in summary of information supplied in first interview related to career and/or employment.

Questions

Is that correct?

Do you have the supports that you need on your job? Do you have support to keep looking for other work if you would like to have more hours?

If yes, Can you tell me what they are like?

If no, where do you think you can get more support with this area?

Have you encountered any barriers? What has helped?

ROLES

You told us that... fill in summary of information supplied in first interview related to roles in all aspects of life.

Questions

Is that correct?

Are there other roles that you would like to have in your life?

Do you have supports that you need to take steps towards those roles?

If yes, Can you tell me what they are like?

If no, where do you think you can get more support with this area?

Have you encountered any barriers? What has helped?

GOALS/QUALITY OF LIFE

You told us that... fill in summary of information supplied in first interview related to personal goals and achievements.

Questions

Is that correct?

Are there any other goals that you would like to add?

Do you have the supports that you need to keep working towards your goals?

If yes, Can you tell me what they are like?

If no, where do you think you can get more support with this area?

Have you encountered any barriers? What has helped?

WHY COLLEGE

You told us that... fill in summary of information supplied in first interview related to purpose of participation in college.

Is that correct?

Do you still feel that way? If not, what is different?

Would you like add anything?

APPENDIX C

FOUND DATA POEMS*

The Long Road to Victory

By TPAB

I pretty much toured the apartments
my original spot
was to choose campus crossings
but after I looked and toured the province
and saw that it was closer
that's when I went with the province
it was mostly me
but my parents had help in that too
I feel great about it
they had a contract
where you could fill out background
of the roommates that you would prefer
like if you don't want a roommate that drinks
or smokes
or do you want a roommate that is messy
or does he keep stuff clean
definitely no smoking and no drinking
and at least cleans up after himself
there are some ups
and there are some downs with it
I'm still trying to figure out right now
ups and some downs to it
I'm still thinking about that.
ther than that nothing really to change

I'm still shooting for meteorology
from what I heard
I have to increase my intake of math and science
I chose
been interested in weather
since the third grade
nothing in high school or anything helped
I've reached out to a couple of news stations recently

**See Figure 13 for demographic details regarding cohort year, race/ethnicity and gender of poet/participants*

I've been communicating with them
on social media as well
I'm actually trying to find a time
to come tour their stations
one of them actually suggested
a live chat which I still kinda like
I didn't want to bet on it
but you know it was something that I'd be willing to do
and I think another thing
I should probably work on
talking more
just a little bit more
more open
I think my communication with other people is good
I think I'm talking more
into presentations
I think everybody wants to know how it goes
college an important step
definitely

have fun
school games
arcade games spots
bowling
mostly with friends and family
I met here at school,
a few back at home
I'm happy with what I've got but
it's like friends come and go
and then it is what it is
cause everybody is not going to be your friend
my parents and family definitely
support me
and a few close friends
it's a good mix
places I go
decided mostly by me
but a few others might suggest it
and then if I agree with it
I just go with them
friends in college
they are people my age
we take the classes,
and a few social media

some barriers
truthfully
there are a few people

whenever I hit somebody up,
they're always quick to try and jump in as well
and being the kind of personality that they have,
It's hard for me
to have them jump along in with these folks..
certain people's personalities don't mix
so I have to be kind of cautious about that
I hate throwing people under the bus
but that's
that's true

Still working on trying to find something in science
science club or maybe a math club
what makes me hesitate,
if other things maybe,
I hate to use the term work
because that is something
that probably could get in the way,
and maybe there could be something else going on on campus,
Blue Crew is always the athletic events,
University band
it was something I enjoyed
the music

Important roles
being a sophomore
a son
a friend
I give advice to people who need it,
especially for other people that have autism
I learn how to control it better now that I'm older
I guess learning to follow before leading,
I learned that you have to follow before you can lead
and to certain people
I could be a leader you know

Supports
my parents and my siblings
one brother, one sister
older sister, younger brother
she actually has a family of her own,
my brother has graduated already
my grandmother
she'll be there as long as she can
advisors

me
I decide on support
hey are working for me
so far
would not change
as of right now
nothing is getting in the way
as far as I see it
supporting my goals
i gotta say yes on that
they're like this will help you,
you may not necessarily agree with it
but this will help you
The majority of it is all me though

In the future,
if you work hard in school
hopefully I can get a fancy house.
fancy car,
start a family of my own
and have my job of being a meteorologist
on occasion influencing younger kids

I talk to everybody who wants to know
about my dreams
I can't be shy about it
I'll put it this way
if grant gilmore wasn't shy about it,
I don't need to be shy about it
WFMY, the chief meteorologist,
role model
just about all of em are
I feel good
about overcoming autism statistics definitely.
I've had a few people
that say oh you're not gonna make it this far
or make it that far,
I want to prove them wrong
I'm in school and
a few of those meteorologists actually know who I am
I communicate with them on social media.
so its a lot of things I'm doing right now
to let them know I've made it this far,
you said I wouldn't make it this far
but look where I am now.
I think I've accomplished everything
I mean there's always that one that I'll probably want later
but as of right now

I think I've just about accomplished
everything
that I needed to do so far
if anything gets in the way
its because I don't want to do it.

Friendship

I know I've been too quick to call so many people friends
when they are really not.
friendship
going with me through good and bad times.
solving conflicts the mature way.
being there when I need you or you need me.
taking my advice when you need it if I give it to you,
cause a lot of people they'll ask for advice
and it just goes in one ear and out the other,
and then they fail
and they come back to me
like why didn't you tell me this
and I'll say
I told you
you should have listened.
more will come
and more will unfortunately go

I feel like I'm treated pretty well,
I haven't had anybody to actually,
talk behind my back or anything
saying there's something wrong with this person or...
they respect who I am
there's always that one faculty,
there's always that one
that gives you problems
I would talk to them and explain to them that
I am not really agreeing to how you're doing this
and if they listen
then you know everything's back to normal
and if they don't,
then I just mute them out
I feel like I have freedom to address it the right way

I guess being at UNCG
it has made me kinda....
a lot of people think that I'm kind of shy a little bit,
being up here at UNCG it has become easier for me
to actually show my true character and everything...
UNCG is very diverse and everybody is being themselves
and so I can be myself here and be happy

me coming out of my shell
was definitely a good challenge
once I get used to being around a person
of course I'm gonna come out
everybody is,
is important in some different form or fashion
so they may not necessarily be too big of a fan of me
being who I am
but you know they respect who I am
I'm treated with respect
I will say that

Natural supports
people who support you
but they're not necessarily getting paid for it
a few close friends
definitely my siblings and my parents
I see them, I see them a whole lot
Girlfriend
that's still in the works I mean
it's important
it's not a barrier,
but I can possibly see it as being one,
maybe telling them that I'm in this program
that works with students with disabilities
not saying that it is one,
but I could see it being one

I feel pretty safe
call 911 yes
CPR, I can't do that
I don't know if I can actually handle it,
or I don't know if it can actually
cause I think if I actually bring the person back to life,
it's actually gonna freak me out
like I did this?
I feel healthy
as of right now no concerns
On break
It feels
very different
coming from a small town with absolutely nothing there
boring
being bored in college
is different from being bored at home
it seems like in college,
there's a lot of people there,
there's always something there that can keep me occupied

and when you're at home
you're just there with your parents and siblings
I have a doctor and dentist back at home
my parents, they look at the time
and they decide for me
one day
I will do that on my own

My rights
education,
dress...
where to live
vote!
I voted at the last year's election
My mom had to help me cause I am not good with politics,
my mom has to tell me don't vote for this person
cause he's like so and so, and I'm like, mom,
does it really matter who you vote for?
but I kind of watch it every now and again,
and my parents they explain it,
and I see why they are not so good with this person...
I'm learning more but I still have a long way to go
that first election I was like
you're going to have to help because I don't know
what this person wants or what this person is capable of doing

A right i can't exercise?
letting kids with disabilities,
if they're talented enough,
try out for athletics
pretty much anything that is forbidden...
like if I couldn't do pep band,
I would take offense to that
like if I told them I have autism in this program,
and they say
oh we can't let you play because of that,
I would take offense-
instead of actually going out to try out for it...

when I had my first job I had some support with that
it took some time but it eventually worked.
no income right now
I mostly have things for what I need
but I need a job
they had this job fair,
the scientists come to the elementary schools
and explain the experiment,
and we do the experiment for them...

I'm waiting to hear back from an email from them

As of right now everything is good
going the way I need it to be
I'm just trying to finish school
and get my education
and get my dream job.

I feel like it
it's gonna be long road
but however way to get there
I'm willing to go for it

Deustch ist gut

By WALTER

I decided to
live in province
because in the past
I had roommate issues
then
I had to just start fresh
I live in Province
my parents , they told me
they found out the old manager at province
said that it was like a good price to live there
and we took it
then I moved there
Its pretty well there
no drama or anything
yeah everything's going well
that was like the only other spot .
we thought it was a good fit
close to the school that I play on sundays
at the EUC
I was involved
everything's going well yeah

my family
the lacrosse team
going well
my dream job is to be a cook or a baker
my parents said if I do well
and graduate
you can go to austria and germany
cause my family is in munich
go stay with them, make a dish for them
if you stay with them you gotta like make food for them
yeah so we'll do that
and to my grandpa's side of the family
go stay with my uncle Norbert and his wife
and then see my cousin
he knows a little German too
I took my second year of German,
I gotta learn more of the language
in German class we learn about the Biergarten
and we learn about when Oktoberfest is,
I'm trying to get connections with Great Harvest,
trying to do a job application

took cooking classes at Williams Sonoma,
learning how to do soups and stuff, in class this sunday
we went there and we learned how to do buttermilk squash soup
that was pretty good for the season
I'm doing an internship with GLC
which is Greensboro Lacrosse Club,
I'm officiating for them
and their scrimmages
that's going well,
one half I play
and one half I officiate
they got a video of me doing that
and it was pretty good
I would play for the indoor team
me and my friend want to do that and Berlin,
do that, and play in championships around Europe
after seeing my mom cook and after my grandpa made breads and stuff,
I wanna do cooking
I wanna do a little baking,
I wanna be doing both,
hopefully learn more desserts
like the ones in France and Greece,
try to learn how to do those two,
learn how to do pastry
make a baklava,
learn how to make crepes
for italian
learn cannolis
learn how to do the stuff directly
I'm still trying to get the resume correct,
and eventually give it to them
try to learn different desserts,
and then go to the scandinavian side eventually, then Greece
when you're baking it will give new ideas

my lacrosse buddies and for away games
we carpooled,
I took the bus
and then for GLC I got a ride from the owner/coach
I go to Western Guilford High School,
or if we have a game for UNCG

I would learn more German, cook, bake
look at music videos, Germany based music artists
I used to DJ at clubs/bars and yeah,
just take another whirl with that
and people liked the music,

I like playing hard style,
jump style,
trance and I like to play oldies
I djed at the hookah bar, ,
the bar guy,
yeah he liked when I djed,
he liked pumping with it
and just having the right music
everybody was happy when I was there
my family is GLC,
Important roles
student and friend and all that, yeah
my blood family and then my lacrosse family
playing lacrosse
officiating
I dj
I want to do both

Supports
BA staff
natural supports
lacrosse family
my old hockey coach
I'm happy
happy with supports
nothing really to change
after I graduate,
me and my lacrosse buddy,
we want to go to Germany and austria,
travel all over europe and find out different cooking and baking styles,
and then go to beer garden and Munich,
and then try to get to see some of my family too in Germany
and then eventually come back to the states and go to culinary arts school
and then go back to Germany again,
try do some research,

Feel good about
ice skating
the first time,
I learned how to ice skate
it was 2004,
my teacher's like
you want to go to one of those carnival things
and when I got there I saw clay aiken
and ron francis and then there was a mascot too,
and there was a big line,
it was a cold december time,

and there was a bunch of people
a red carpet
and I put ice skates on,
and my parents were close to the glass,
and i'm hanging on and
eventually I see this professional guy,
a professional hockey player,
and he comes and he tries to help me, like get off the boards...
Now I play on the adult team
I like to skate backwards a lot
I played against this other professional hockey player too,
that used to play for the hurricanes,
shane willis,
was like part of the junior hurricane organization,
and one day too,
me and him was playing against each other
and I got on camera,
I got on video,
a giant camera with a microphone,
and I was like okay, they were interviewing me
feel good about
driving my uncle's boat
proud of
being the captain of my hockey team

a friend like stands by your side
and helps you accomplish
or just is nice to you or something,
try to help you like accomplish your dreams
not enough friends
its only like outside... in the school
it's really tough,
especially when you have more friends out,
and then when you're here...
not as many

Sometimes
people think I'm important
Sometimes
people don't listen to me
around school or something
not faculty
not staff
students
I'm not trying to deal with anything of that...
If not treated well
just tell somebody

you can't let it be on your shoulder
for the rest of your life
eventually the pain...
having the urge in your body
and when you're passed on,
they'll probably feel it more,
now I can't do anything about it
do something about it
while you're still living

I'm close to
my mom and dad and family,
and then guys on GLC,
there's a few others
folks I can rely on
and I was talking to somebody
I mean I was talking to...
well I'm friends with them
Being involved
if it happens,
it's important
no friends for advice
not really
the guys on GLC will be like funny about it
talk to family though

I feel safe
if they try to mess with me...
well I don't think they would,
I'm big and tough
I eat like organic food, that's fresh and a bottle,
I can't have plastic,
I can't stand mixes either,
any desserts from mixes...
cause in other countries they do,
and here they just buy all...
when you go over there they have nice fresh chocolate...
and eventually want to have a garden or something
eventually I just want a house,

Doctors and dentists
I make appointments
I have
right to vote,
right to own a house,
right to go places,
right to have ID or driver's license,
right to live in a country or state

the country and the ID
most important
exercising my rights
no complaints about treatment
I would tell somebody or something
my family

Working on goals
I have money,
I had a summer job at 21 as dishwasher
enough to do what's important
eventually I save for speakers
My file
no one else can see it without uh permission
protected information

college
I want to find out what the future was for me
and just have more knowledge
eventually try to figure out what you want to do after
decisions and stuff
got close to people,
taking a foreign language
so I can go over there for a while
study abroad
I haven't been able to
but I wish I had
Deustch ist gut
Deustch
ist
gut

ANNABELLE's Poem

My parents looked at a couple apartments
I was with my friend
and they decided it would be best if we lived at UV
I love UV because I live on the fourth floor.
means that I don't have to worry that stuff will get stolen.

Even though house
is the weirdest house on the fourth floor.
is kinda like haunted.
haunted like stuff goes missing sometimes
or it smells different smells.
Me.
I made that final choice?
I lived with my best friend.
we had to go separate ways.
We get to..
We get to have fun with each other.
We don't have to fight all the time which is quite nice.

.
Dream job was to be a navy seal and military,
but I found out women cannot be in combat.
So I decided that was out.
So I wanna be a music teacher.
and teach music
teach students how to sing properly
so they won't strain their voice
like a lot of singers have.
I'm excited, if I get it,
if not I will-
I will find a job that will be simple for me
if I can't get my dream job.
Right now I am working at Pediatric Possibilities,
which I really enjoy.
I help them get stuff ready
I make sure everything is good to them..
So the people who do therapy with the patients..
don't have to worry about it because I took care of it.
Yep I'm working at an internship right now.
I'm trying new things this year.

learn how to learn in an office setting like..
learning what to do on a list
like if I have something to do..
know how to do it correctly..
and also seeing the kids smile and crying,
enjoying the fact that I get a job there.
which I decided not to give it up
because I knew if I did
that it wouldn't be fun
I have patience for them.

Not really anything I can't do
Not really any place I can't go
We normally do to get to the mall.
we take route 71,
but if it's crowded we take route 2.
if I have to stand I will, but I hate doing that.
people are selfish somedays
they just say like get up.
I had to do that the other Saturday ago it was not pleasant.
cause I had to stand on 71 with my friends.
we had to stand
our hands were getting tired.
On the other one
A lady stood up for me and said
you need to get up so this lady can have a seat a
and the other guy smiled at me like you did the right thing.
the lady was advocating for me.

I go to UNCG.
we go to a movie once a month,
we see a movie
or we go to the mall.
to be honest,
and spend money I have to say.
we take turns so my roommate got to choose the movie..
the Friendly center is where we wanna go,
we take the bus and we always have a plan to get there.
So we don't have to ask staff normally to come pick us up
I've been really good at tracking my money..
this week- this year
I usually have this computer document that has it
and then I write it down.

If I need to be in a stopping point
I literally stop myself and say
“Self I can’t do this right now.”
My my parents taught me.
Or I taught myself.

I know a lot of people in my community
my mom’s friend a little bit.
my dad’s friends from work know me
my friends I hang out with.
like some BA students I like hanging out with.
I did when I was in the peer companion group.
but right now with my schedule I don’t really have time for it..
I have to manage my time wisely.
I’m a good understanding kind of person.
means that if my friend couldn’t do something
I say “Okay I understand.”
me and her understand each other very well.
I like to cook.
I cook with my roommate
and she-save money.

there’s one lady at Walgreens
who I always ask about her day
and she always say thank you for asking
I said you’re welcome.
and then I go to Walmart and just ask how the day is..
it’s always fun to do that with people.
sometimes I give blood to the Red Cross
I do a volunteer job.
at the Starmount Living Center.
I play the piano for the elderlies on Tuesday.
It’s pretty fun..
and then I also work at the restore, volunteer there..
the project that we are doing at this moment
is gonna take time to do it,

Roles
one is being musical.
being helpful..
being loving to somebody.
being a daughter to my family and being an aunt in my family to my niece and my
nephew.

even though they get on my nerves half of the time.
but yeah I love them for who they are
I'm a granddaughter to my mom's dad..
.and to some of my aunts and they are aunts to me,
but I count as a granddaughter to them.
sisters, we count as sisters.
I help her and she helps me.
I am a good peacemaker sometimes.
To my friend when she really needs- needs me.
When she breaks down sometimes
I can help her solve the problem.
Sometimes not all of the time.
It depends on what the problem is.
A student.
I want to graduate
Sometimes I help with transportation.
knowing the time we have to get there.
.and one of the biggest things for me
is accepting people for who they are..
Yes, I'm actually, um, happy for who I am.

I use on-call
my family.
my mom especially.
Its enough

Deciding on my goals?
me,
but sometimes I like talking with my mom about it.
final decisions about goals
me.
My goals
have a job...
an apartment.
and try to get around so that I can like get to the places I need to go..
near my internship.
I really want to live in a mansion.
I can't afford it I'm not rich.
when I graduate some of my friends
I will still keep in contact with.
my family as well.
which is one of the things I have to do every day sometimes.

One thing that I feel good about

was calming my dad at a Verizon store.
which for a daughter isn't the easiest thing.
Because I was hungry, we were both hungry
so I had to think:
and say we are gonna sit here
and the nice guy said "thank you we're very sorry"
and I'm glad that I calmed him down. It's not easy.
and the other thing is playing the piano for the elderly people
even though I'm still learning how to play
My mom is the best right now
She helped me decided not to quit
I'm about to quit
and I decided you know what that's stupid.
I'm glad I didn't quit when- when- I'm glad I didn't quit.

I think one of the things was,
I had to just decide in my life like am I really gonna play the piano?
I had to choose.
and I'm glad that I um decided to play the piano not the flute.
I'm very glad that I chose, not an easy question to play,
I had to play it out that way.
now
playing the piano for the elderly.
reaching my dreams
learning how to play in that kind of environment.
It wasn't easy. I was nervous, but I kept on going.

Going out with friends
I do it on my own.
A good friend would be somebody
Who trusts you,
and stands up for you,
and understands you.
somebody who you can really bond with in your life.
that doesn't be mean to you.
folks treat me very nicely.
fairly
respectful
listening to me
like I'm important
taking the bus was challenging for me,
because I had to be brave about it.
and finally I said to myself
"you need to stop being a baby about it and do it"

and now I love the bus.

Natural supports
my mom, my dad, my sisters, and my brothers.
My friends
I did date my Freshman year with
and we decided,
we decided to be friends.
and so that's about it right now.
maybe in the future when I'm ready.

Feel safe'
feel healthy
making doctor's appointments
I have to make them.
even though I'm afraid to talk on the phone, I have..
I'm trying to get out of that.
when my roommate is here she's like-
"it's not gonna bite you, you can do it."
she said "I have the same problem,
but I'm learning how to get out of my shell and do it,
even though I don't want to do it."
talking to myself some days and telling myself to knock it off.

Going home for breaks
amazing!
because I get to see my family and have family time with them.
and I get to give my roommates a break
since we see each other a lot
we can still contact with each other
I mean talk with each other.
Yeah it's like my mom
always thinks of the song *Slip Through My Fingers* from *Mama Mia*
The way she seems to hold the actress daughter in the movie
is how my mom feels.
I feel The same way.
but I'm glad I get to go to college and get an education.

I have the right to go to college.
I have the right to go places.
I have the right to vote.
That's all I can say.
I can vote.

I can do what I want.
Have everything I need
My record
My grades
About me

College means to me that I want to have an education,
and I want to graduate,
and have a job.

PUDDIN's Poem

I walk on campus like everybody else...
I feel safe
the way I feel safe is like,
if I'm around a lot of people, then I'm fine with that,
I'm comfortable...
but if I'm not around you know, nobody,
then I feel like somebody gonna, you know,
get me or something
I walk with a buddy
I use the crosswalks
in the night time I stay in the house
feel safe at home
unless I'm with a buddy

health is good
I watch what I eat, exercise little bit
not a whole lot but...
I would go to student health
went one time
it was okay
yeah it was
I'm healthy

its kind of hard to meet friends
back at home I do...
but here I be trying to like,
find friends but they be acting stuck up
some of the people that's outside of BA
and inside BA
see they got they own crew,
they don't want nobody else
tried hanging out
I know I had hanged out with a freshman
I hanged out with her a couple times, but I don't know,
she just be staying busy

I see my family
I talk to them on the phone a lot,
but I don't see them like that
just like the holidays
now that I'm comfortable,

I'd rather see them like on the holidays...
or sometimes on the weekends
they support me
if I need groceries or something like that,
then they'll like come down and help me out
because my food stamps
they cut my food stamps low
I make decisions by myself,
but they be trying
they think that I'm not ready to be independent
they be babying me too much

CCS, they was okay
but I didn't like that,
you know they was on they phone's too much,
they was talking to other CCS,
they wasn't paying no kind of attention like that to me

I'm just like past it
its like when I do my chores or whatever,
every time I do my chores,
they was on my back,
seeing what I'm doin and stuff
I feel great not having them on my back
cause I know how to do...
it didn't stress me cause I feel like
this program's not really organized like that,
they say that they will help me
but then they switch it around
and say we can't do this or we can't do that
they'll put a staff that don't know what they doin
and then the staff,
it seems like we have to tell them what to do
cause they be like,
well what y'all supposed to do,
how yall do this and how yall do that
I be thinkin like, why is you here?
the teachers...
they can be off sometimes
like they don't know what they doin...
the stuff that we're learning,
it seems like the stuff that we're learning,
we learned from freshman and sophomore...
it would be better if they just changed up a little bit
not too hard, but different

different stuff
like with the management and stuff like that,
I wanna like see something different

like I know how to grocery shop,
but we just talk about, like rent and stuff like that
more about taxes

I don't like telling them everything,
cause I be thinking they might go back and tell somebody
like tell them you know, tell them not to
they keep it private

I live at university village
me and my parents, we had like,
been looking around and riding around.
I seen that one and it was the closest.
so I said, okay well let me try that
my roommates
the two of them, they good,
one of them she just weird sometimes,
they drink
but they drink on their time,
like they don't party they just sit down and drink and talk and stuff
comfortable as long as they not bothering me
the only thing I like is everybody stay to themselves
I got them cause I was living downstairs
but then it was the other roommates...
they like to party and stuff
I just told the people in the office to change me
and then I had to pay like 200
Im gonna stay there
I was gonna like look for some more houses, but...
I want to live in a house, not no apartment
a house in GSO?
maybe somebody could help me
my staff
the QP

I want to work
yeah I do
like get out and look and put in applications,
go online and see what they have
as soon as possible cause I need a job
I'm tryin to find something that would relate to my career

like hair
like under somebody,
that do hair
I'm doing an internship on campus at the theatre,
something like that, in that room
I like it
I'm in the gospel choir
I go to church
its off campus but its like students, for students
I go to the mall. Movies
I like going bowling though
with a buddy
somebody I know (laughs)

they asked me about services
I have them, like staff
I think he could do more
like focus on the, okay, the stuff, the house situation
I can talk to someone and change that
if I wanna go out, I can go out ,
I have the right to vote
like to speak up at meetings
learned about rights in class
human rights
feel respected
Sometimes
I wanna keep living in a house,
but my aunt, she just afraid
I wanted to live down here,
but she want me to move back home
have to tell her
I want to go to hair school
go back to hair school
maybe somebody can help me
someone in the program
do research
my goal is to finish here, um go back to hair school
get a job
find a place,
and I want me a car
Im working towards a license
well I need somebody to help me with it
maybe staff

oh, and I just want this program to be better

MARC's Poem

I am living in spartan village, union hall
I like it a lot, it's very nice
roommates, not so well
its cause the one next to me is making a lot of music
I was talking to someone in the MHRA
to help me with my problems, living in spartan village
It's helpful
I decided to pick union hall
I picked it
if I could change anything
I would not like the walls to be very thin
because you can hear every conversation

my dream job is
I want to do business
like entrepreneurial
owning my own restaurant
I decided that
I like cooking
I was looking on the internet
and figuring out what steps I'm supposed to do for the business
mostly I did that on my own,
and I got like help from my uncle,
he owns his own business
I want to take classes
building your own business
ask people or my advisory
is there any way that I can learn how to build my business

I'm in catholic club,
meeting new people
I like it a lot
I'm connected to soccer events
I am into anime
my other roommate
when I was a freshman and he was a sophomore,
he showed me,
I mean he told me that there was an anime club
I liked it

I go to the rec center
lifting weights,
running on the track
I wish I played for the team for UNCG

soccer
the program, it's really tough
Getting a degree
is a barrier
I would change that
something that is getting in the way
is that normally
I want to take classes that I want to take,
sometimes, right now for this semester, I have short classes,
but I want to take a couple...
More choice
business and french
those are the main ones
I want to be in a fraternity
like my buddy
a peer companion
I am going to check it out

I like to go downtown
go to events, like concert events
I know what's going on because
one of my teachers tells the whole class
that there's events going on downtown
I go on the internet
I also go to the EUC
talking to the person who works at the front of the desk
I choose these things
me
I normally like spending time with friends
I met friends in the program,
and I have one friend I met at a soccer event
sometimes barriers,
more like building my self-confidence with people,
and sometimes it could be awkward
meeting new people, like in the caf,
but sometimes I wish there was more people that I could talk to
not a bigger circle,
because it's going to be hard for me to remember all the names
just a few more friends
my supports, my advisors, and teachers
they help me
I feel comfortable

things that are more important in my life
are getting good grades
being a student
building my confidence, meeting new people,

taking care of my health,
which is very important to me
what is important to me is that I want to get my license
I want to be a driver, yes
I want to get a job too
I want to work
also, I would also like to,
learn how to dance
Be a dancer
hip hop dancing, maybe learning how to do salsa
taking classes
I would like to do that
I would be nervous, but...
most likely, I have to wait patiently in getting my license,
which is very, very important to me
being healthy, it can be tough
because sometimes the sweets can be very tempting

CCS

they help me
they normally help me with the things that I need,
that I need help with
like if I want to go,
if I need help going on the bus,
the big busses,
GTA,
going to the grocery store and getting food
sometimes things that I don't understand
homework, if it's too difficult
I decided on supports
and they do work for me
building my self-confidence
If I'm not happy about support,
I guess talk to my advisor,
explaining if I have problems,
and they would try to help me
After I graduate
I would like be my life,
having my own apartment,
I would probably live in florida
I have a father there
I would like to have a car to drive, and work
also traveling too
family,
family,
family,
I would like to help my mom,
like pay the bills, that kind of stuff,

because I have to be responsible
do good in college
getting good grades
which is the most important.
studying
I decide my goals
cause I'm my own person
what I feel good about is that I'm a sophomore
which I am really happy about that
I try to talk to some people
accomplishments that I feel really good is
I normally have a talking to my grandma, family members,
spending times with them
before I start to going back to college,
and my mom too
I feel good about that
I feel most proud of
that I'm living in spartan village
and that I'm being more independent
Its important not getting nervous around other people
when I'm presenting like a project

A friend is like hanging out with them
more like having the same exact interests sports
well mostly in sports because that's important
meeting his other friends,
going to bowling
going to movies
this semester its very complicated
because my other friend
is like an RA on another campus
But other than that
having my buddy from my peer companion was a lot better
I'd like a few more friends

I am treated with respect
treated fairly
like I'm important
If not
I don't talk them
I'd talk to my advisor
I can count on family
sometimes friends
because I trust them
my natural supports
my mom my grandma
my family and my friend who lives in florida in Key West I
trust very much

that is very important

I want a romantic relationship
not having a counselor to help me with like my problems
gets in the way

I feel safe
well on campus,
I'm safe but if I was like off campus then no
It's different because on campus is like where there is a lot of people
and it's not like you're going to like a supermarket by yourself
and there's like RAs
and there's also like a police station sometimes that is very close
always staying with a group, having a group of friends that way you dont
I don't feel like lost
I have a new app called life safe

the most health concern
is that the sweets
like it can be a very big thing sometimes,
and I don't wanna like plan on like being very fat like
it's hard to resist it like
Doctor's appointments
normally I do it because there are some like on campus,
and also I have an aunt who's like a nurse and so I have her number
When I go home
its very complicated
just because when I was living back in wake forest in north carolina
when I was like a freshman and I was living on campus
and I came back home
I felt like I don't feel like being here.
it felt different
because I was a lot more independent
and if I come back home
I don't want like my parents always helping me do this do that
depending on my grandma
my grandma is always helping me out
it is very hard to let go.
she says that every problem is her
I mean my problem is her problem

my rights are that I have my own choice
in whether I want to work
I don't need a lot of help because
I need to do this on my own
make my own choices pay my own bills
a right to have money

right to vote
I have voted
It felt good
the thing that I want to have
I want to have like more like driving experience
but I didn't get that a lot
I'm gonna have to get a job
that way I can pay to get my experience and drive
Not respecting my rights
sometimes my family does that,
and then I don't like it
cause it feels like I'm not taking care of my own
I talked to my grandma
and my grandma says "I don't do it. I don't do that"
But sometimes she does
Yes

My staff
It's working
my advisors... they're good
I get stressed about money
I do
I'll talk to family members
my supports and advisors
If I could I want to like spend it wisely
I can work on it while I'm here
with my supports

I have a right to see my file
not a random stranger

Why college is,
it's very, it's like very amazing
to meet new people learn new things and
getting a good job
and like helping my family too
I'm learning
like standing up for myself
having like good advocacy
I'm learning
learning
and that is important to me

RACHEL's Poem

I want my own apartment
and my own job
I would like to see
a lot of things
and a lot of places
I would like to drive a car
maybe have more friends
more money
performing
would be my goal
for my dream
learning so I can do things that i like
in the future

To be a successful person
I need teachers who help me
to exercise and eat healthy
to be safe
stay on the sidewalk
out of the streets
never talk to strangers

Having my family and friends
watching movies
reading
acting and singing
going to college
and being smart
doing what i want
and being with people
matter to me

I want to study drama
be at UNCG like my sister
and my mother
I want to enroll in a degree program
take the SAT

I volunteer at the boys and girls club
talk to them about being nice
and not being a bully
I volunteer at my church
and welcome everyone when they come in
It is important

staff can help
I feel safe
can call 911 if I need help

I do not like my body
managing weight is important
I need help

The right to vote
and right to privacy
are most important to me
I get to decide what I do
And where I go

I spend time with my mother and sister
they are natural supports
I would like more friends
I want to be in a relationship
need help with that

Roles that are important
sister
student
club member
satisfied

Before college
not doing what I want to
and not going where I want to go
was not working

Now I feel accomplished
by getting good grades
being in school
almost finishing school
furthering my education
learning
to be an actress
own a house
have a boyfriend
own a car
and live
on
my
own

GOOD GUY's poem

I feel real safe
learning how to walk across the street
using the crosswalk and stuff
and knowing how to get around
walk, bike and bus
just,
just walk in safe areas
keep doors locked, especially at night
this is important
no time that I didn't feel safe
not that I can remember

My health is improving by...
I eat out once a week or twice a week,
it all depends.
Popcorn
that is the only late night snack I have
And I've been working out
at least a few times a week or every day
use the treadmill, sometimes go walking around the track at the rec center
I feel good
Doctor's appointments
Dentists appointments
my parents would schedule for me,
back in my hometown which is Durham.
but for me
if I am staying in Greensboro
I have to schedule them myself.
I never scheduled one myself
I would feel good about myself
being independent
In Greensboro
I'd take a bus
I take showers,
put deodorant on,
brush my teeth,
wash my face
and brush my hair
and I put some acne cream on too...
yep

i have the right to do anything I want to do,
like have friends,
be independent,
not have people tell me you can't do this, you can't do that.
I can do whatever I want to
I don't have the right to steal,
do any other illegal things

sometimes my roommates would get on my nerves,

and I would tell them to stop
sometimes they'd keep doing it
keep telling em to stop
I talk to someone
like my mom,
my dad,
my psychologist,
my teachers and stuff
they talked to me about it,
like how to stop and stuff
it worked
when you say
can you stop,
and they'll stop right
Now it's better
I never got hurt real bad

My staff and stuff
share information
with permission
applications about myself
Invitations to invite different people
With my permission
it was well

My staff
they help me with stuff,
like clean my room and stuff
they do it with me, help me
take me grocery shopping sometimes
help me look for apartments to live in
I found one
its near my work too, on spring garden
looked it up online
visited a few
scheduled appointments on it
I chose it
Living alone
I feel good
I have the right number of hours
BA
they help me with my senior portfolio,
and my career, getting a job.
like I have a job at honest one auto shop
as an auto shop assistant
I chose it
cars, I'm interested in cars and stuff
I looked around for it and chose honest one the place
it's convenient to my home, my apartment, and uncg
they're nice
get paid
Want more hours

After I graduate

I have quite a few friends
in the program and outside of the program
both
we like to go to different places and stuff
go to fall events and sporting events and workout
events and stuff around the campus

calling them
as often as I want to
go out and eat places, at different fast food restaurants,
go the mall and stuff,
go to like sporting events on UNCG hang out
I know how to get to most places by taking the bus
I volunteer at salvation army on lee st
I feel good about that,
I get to help out with clothes and stuff
it was my choice what I wanted to do,
to help out with clothes and stuff
After I graduate
I might concentrate on working for pay
its a good place

I go to church
my friend told me about it
And I keep going
come worship, sing
with everybody,

I want to stay in Greensboro for a little more,
like for a few more years, yeah
Then go back to Durham,
four years to be exact i guess
maybe one day become a master auto mechanic
maybe go to grad school
grad school back in Durham
get my own apartment,
keep my work

My Poem

By JASON

My parents told me,
well my parents and I talked about it
all the time together
with my siblings
it was my parents
they decided
I decided about the Province though,
I had to agree with them though
after I tell my parents
I'm going to live in the same place
they respected that
big support

the apartment complex people
decided on roommates
lottery
everything so far so good
the people... the roommate
I'm happy now
will talk to the manager...
their person who is at the front desk
If problem

my dream job
that would have to be the bowling center
in my hometown
Mom and dad decided
I felt pretty good... I felt pretty good about it

I'm not sure about the living on my own
I'm not so sure about it
cause living on my own
I would have to pay the bills...
the electricity bills, utility
it's just...
that's gonna be, not easy for me
the finance piece, yeah
I think it's the money
Makes me nervous about graduating
The money

Working at the bowling center
I think it was something I have to do

A job that I want
I felt pretty good
want to keep on helping out
important to me

Parents help
figure out goals in life
steps to dream job
i've taken finance class
entrepreneur class
the internship class
I say its been very helpful,
and I think I'm getting better...
I know how to keep a budget
the internship from last year
one of the things that was kind of hard for me a little bit...
the prices were confusing
At spartan trader
sell things, sell product
did a little bit of customer service...
helping with the manager
learned important things
it was a good experience
my instructor
hes helping me find a job
as a cashier
work at bowling center helps

Something I haven't been able to do
sports
like bowling
but planning to
at the AMF bowling alley
join a league
I figured it out yesterday morning

People that are like bossy,
keep me from doing things I want
like hanging out with friends I guess
like my roommate
I like to play pool
yes i do
My roommate
he introduced me
to students in other departments
they're really nice
I usually watch them play...
i usually watch them at their home game

such as softball, volleyball, I
when they're heading to class
hang out
with an old friend
talk and chat
If unhappy
talk to my parents probably...
or my siblings
or my brother in laws

I volunteer
at triad lanes
at systec with computers
they fix computers
and they look at it and see what the problem is
I just usually shadow... opportunity
I haven't started yet...
I'm going to
being involved
that's pretty much it

Roles
role model
a helper I guess
son
Important role
a student
Important role
and I was going to make it friend probably...
a buddy
I think that's about it
feel good about that

support
a tutor
when I need some help with questions
in advising, that is just me
I decide
my dad
he just pays the check
I make decisions about my life
myself

my life
after graduation
My north star
i put a coach
a bowling coach

I put a girlfriend
professional bowler
find a place on my own
find an apartment or house...
find the closest place
I think I wanna get a car maybe, instead of walking
a license
yes
I just did it on my own
I just came up with it on my own
my parents can help
my sisters
my family
support network
campus support
support with goals

Felt good
getting good grades probably
passing midterm exams and finals
proud of passing them
working on getting up on time
cause I sleep late and it screws up the schedule
working on it

I like to go to the lost ark
go shopping
check it on the internet
I can do them all on my own
friends
they can be trusted probably
truthful... um, always have their back
nice...
probably like to have more
instead of being home doing nothing

different people like getting on my nerves
gets in my way
always repeating the same stuff which is a big headache
their schedules

I feel easy to get along with
easy for me not getting stressed out
treated fairly
by staff and faculty
talked to with respect
treated important

Count on
my closest friend in my hometown, from high school
my family
I talk to them always,
when I need them for something
girlfriend
I'm still looking for one
not easy to find
important
there's just too many of them,
I tell my gut to get one but I don't know

I feel safe
yes I do
In an emergency
just dial 911 I guess
Feel healthy
no concerns
Contact
my primary doctor in my hometown
makes doctor's appointments
they would call me

On break
I feel easy and relaxing
On campus
stressful and complicated
At home
relaxed

I have a right where I am heading to,
I have a right to make a phone call,
I have a right to...permission to leave,
I have a right to use the bathroom
I have a right to print out a syllabus
Nobody keeping rights from happening

Rights stepped on
One time
last year
roommate
two other guys that lived in the other campus apartment
they tried to get me to go to some club,
and I said no, cause I just didn't want to
and I felt uncomfortable
But I just exercised in the gym at the clubhouse
One time

one of the sophomores
one of them was being mean to me
another student
he got mad at me, told him his cell phone ringing,
he got mad at me and said the word shut up to me
in front of my face
I was a little scared about saying something
talked to the instructors
they gave me some advice and tips
got resolved

Have income
pays for household
have what i need
my finances are coming along
have what i need
My record
permission
just me probably, just me
I think the employees
If I don't want
must be respected

I feel like college has changed my life
like going to classes, day to day,
learning something new, textbooks, class assignments,
looking it up on canvas
using the syllabus
making life better
keeping on track with my financials
finding the buildings, getting around with the maps
keeping me alert about things happening on campus
Making life better

TORRES Poem

You know I have family went to UNCG,
my aunt in the eighties
my sister-in-law in 2005
I've been to campus a long, long time ago.
for me,
I'm from the suburbs
we don't really have as many problems
like as far as at the inner cities.
I don't hang out in the inner city,
I'm no fit for that since
I'm the nerdy black kid,
being in the inner city I'd be the first target-
I just don't go there.
it's not a perfect world,
but if you don't go to certain parts of town,
you're not as likely
as likely to have stuff happen.
Or just walking with friends, I like to keep it simple

I was raised by an interracial family,
and you know I received a lot of criticism for that
they thought because I was raised by a white family,
they thought that I was better than them
calling me an Uncle Tom and a sell-out,
that is very offensive
Like for me
there's a whole stereotype that men only care about their fitness
you know their bodies
their societal health, not really their image,
and I really hate that stereotype,
it's kind of sexist
just because if you're a man
and you're in good health
and you want to look good
it's considered feminine,
just because a man wants to look good
doesn't make him gay.
For me you know I kind of like body appearance,
kind of like the modeling aspect of health
I'm family oriented, you know
and You know the ICS

I do give them credit
they are a good organization
but I think at the same time,
you know that one thing they can improve on
is being more mindful of family-oriented students in the ICS,
because some people come from culture,
I guess you could say
it's really not bad to have your family help out
it's not a lack of independence
I'm not saying to have your family tell you who to date
and all this other nonsense,
I was just saying some people say
hey I want to live with my parents because it's free rent

I think everyone has the right to be protected
you have the HIPAA law and the FERPA law for education
I exercise a lot of rights,
the freedom of spirituality-
 I don't really believe in religion
 I believe in spirituality
 I believe in the freedom to believe in what you want to believe
what it all comes down to is to exercise that right.
it's so crazy, kind of like a sociology thing you know,
some people don't know about the rights that you have
A lot of people think just because I'm black you know,
technically I just don't have any rights
that's not really true
you know
a lot of controversial rights
the right to be free from cruel and unfair punishment
education,
now they have more on-line education courses
it's more accessible these days,
the freedom to get married and have children
that's something that I exercise
and now in North Carolina you have the right to gay marriage,
not really for me,
but you know I have a lot of friends who are gay
I think that's equality
we have the right to transgender rights too...
everyone has the right to be free from discrimination,
social discrimination
racial discrimination
legal discrimination

one of my 30 year old friends from back at home asked me to sign a petition
to legalize, I think it was gender neutral restaurants
I have friends of all ages
30 year olds who are hip
In my experience
I consider them to be my natural supports
They're good friends and we discuss all these touchy subjects
my friends at the ministries
we kind of believe in the brother sister thing
a deep down belief
a personal belief
is the best way to phrase it
it's kind of interesting, like cause no one really uses,
or goes up to people to ask them for their digits anymore
now they do it online
I've noticed that from my experience,
when I meet people in person,
I never can really relate to them
you never know if they like you as a girlfriend
or if they like you as a friend
on the dating site they'll tell you if they want to be friends
or if they are looking for relationships,
so when you ask someone out on the dating site
you don't get the awkward question
is it a date?
I was just wondering is it something that I'm doing wrong?
I'm just doing what all the other guys do
but t something is just not right,

and then there was one CCS
she would always not give me my space
said I'm gonna call you out in the store,
and she would call me out in Food Lion, cause I wasn't buying things,
see for me, I'm not really good with math,
I don't really function that well when it comes to math,
you know me and science get along,
me and creativity get along,
but when it comes to numbers that's when you've got a problem-
not only that,
Some ccs, they were just coming...
they weren't helping us
weren't helping us naturally get connected so,
they were just coming over to boss us around.
They would come to our apartment

and just sleep at our place,
which is very rude,
I mean why would you come to our apartment and sleep
the whole time you were supposed to be working...
I guess you know when you're 19
and you're in college and you're just adjusting to it,
you kind of go through a lot more stress
you have some maturing to do..
you know now, I would just ask them to leave,
the simplest what I would do,
I don't have CCS anymore, if it was that case
I would say, I think I refuse services today you can just leave,
and I'm probably going to let your
supervisor know you were falling asleep at work

I think when Beyond Academics first started,
everyone was used to giving people you know extreme
supervision,
yeah, like they were responsible for you, this is
the way that medicaid was set up at the time,
so you didn't really have any time to breathe like
they think they are restricted in a way,
but they're really not,
guess some CCS thought they could take advantage of doing that to people

Less intense supervision
gives students more room to express themselves
without having someone telling them
do this, do that, do this, do that,
letting them voice their...
have their voice,
I would say the big changes are I've matured,
you know,
it went from beyond when I was having problems with CCS and stuff,
to the point I was starting to express my identity,
it turns out they thought
that I thought
I was better than other students,
you know when you have Asperger's
sometimes you come across as arrogant,
but it's not an intentional thing,
cause even Albert Einstein, he had Asperger's,

I learned not to room with someone with the same disability as me,

and its not for an ableist reason,
its more because when you room with someone with Asperger's
you get the same imagination,
so you tend to play with each other too much,
that's been my experience
my first roommate, we go too comfortable together,
we had a brother/brother relationship
so sometimes we would horseplay a little too much
and things would get out of hand

I'm involved with a lot of ministry organizations.
sometimes I go to sporting events, play ultimate frisbee,
you know ultimate frisbee
anyone can just show up on campus and play it,
there's no sweat about playing
and I do the sociology stuff,
you know protesting for different things.
I actually started a movement,
its online and a lot of UNCG students are connected,
kind of bringing effeminate straight men into the mainstream
because a lot of men who are effeminate and straight,
if you're labeled a man and you dress effeminate, you have to be gay...
I started another movement where race is a social construct,
cause we're learning from different countries
that have actually taken race out of their government,
I was learning about how France took race out of their government,
so we're a movement to try to do that in America

You know I work at Elmo's diner,
I've been there ever since high school
I get along with everyone at Elmo's
the boss I have a good relationship
I go up there and bus tables and get the job done,
and they pay you decent money there,
there's been times I've made eighty dollar tips, depending on how busy it is I
would say in GSO I've been kind of connected,
I've helped Ateba out,
The Autism Society helped me get connected with Ateba,
I helped them set up for a show the other day,
there was a big show going on downtown,
at the Green Bean and I helped them like assemble equipment,
it's a good music experience,
cause being a musician and I've just released a new single recently,
because I'm actually officially in a band now

I'm releasing our first band single
I've got a lot of opportunities to get out
I am a big advocate for equality
for equality specifically, you know disability rights is equality,
all of its equality
you know I'm also a straight shooter too,
I kind of laugh at things but you know I have a point
you know when I say something I usually have a point,
and even though now I've been able to get blunt with humor
I guess you could say,
I'm more straight forward than I used to be,
and when you're more open, well it's good to be open,
but when you're nice about everything,
I've learned that sometimes you can be taken advantaged of
like its good be humble,
but at the same time it's good to be straight forward,
and why not be able to laugh while you do it
I get most of my supports from Autism Society
they send supports out, on other times during the week,
they help me get connected with the internship
with music specifically,
like I do an internship at the church and whenever Ateba needs me
I help him out with his shows

you know some services I have to have,
it's not really optional,
but I will tell you this,
an interesting perspective
I want to get it on the interview,
cause some people really don't know about it,
one thing about services in Durham,
there are some progressive people
that think services and friendships go together,
and that's a controversial topic but
a lot of the hippies over there they were saying
hey if you work with someone
you should be able to be friends with them
and that's what they believe
I kind of agree with them,
and I think some agencies
they don't want professional and friendships to mix,
but I think at the end of the day,
here's what I think,
we are all human,

and professionalism is good
but I think at the same time,
sometimes we kind of let it dehumanize us,
and that is something that I really don't agree with

I do have music out,
I just want to do more shows I guess you could say,
I get opportunities on reverb nation,
invitations to do shows in different places,
and the only thing I need is the transportation,
and then I can travel around the world and do shows,
and then just have a job on the side,
and then later on down the road
I make more money on my music,
my whole goal was to work at Elmo's,
get a job doing sociology stuff,
and then do my music on the side,
because I'm already doing music on the side
you know getting married is not that big a deal to me,
I might just want to date for the rest of my life,
And you know just work,
eventually build a house in the area later on down the road
I already have a place I'm renting, and I'm moving in

I think when I get old, I want to age,
we live in a society that is pretty ageist,,
so just aging well is really a lifestyle that I really want to live,

I want to say that I chose to come to this,
to study ICS for a good cause,
you know like being in the ICS I just learned a lot,
but in terms of coming to college
I could make a change in society
I went to a high school,
high school told me I would never have a future
or that I would never go to college,
and now,
I've been given the power to know what my rights are,
to know sociology,
to be a scientist,
kind of a certificate in social justice
I came here,
its like they thought I didn't have the qualifications to go to college,
and they were making all these assumptions about me,

its like you know how really in high school you're not yourself?
like I wasn't really myself in high school to be honest,
I used to wear my pants hanging off my behind,
I used to not speak proper english,
but you know that wasn't really me,
I was just trying to fit in with the other kids at school,
you know high school these days can be like a hellhole,
I'm not going to say it the other way,
but when you go to high school and you are not mainstreamed
you are an outsider,
And you know college is different
I came here
I chose to come

Living the life that I love

By MINNIE

I have always felt comfortable
I felt comfortable around UNCG's campus
using my pedestrian safety, when I walk across the street
walking safely to get to class
in my apartment
Me and my roommate always keep our doors locked
remember to lock it with a key

Every morning
I try to eat a banana or apple sauce
That's what I have for breakfast
each morning

I have rights
I have the right to go to school
College
I have the right to be a college student
I have the right to be anything I want to be
I have the right to make my own friends
Friends who treat me nice and sweet
I feel like I am treated fairly
When I am respected by other people
Other people who are not mean
Who look me in the eye
Who are friendly and who listen to me
I like the person that I work with
My support, I'm good with what I have right now
I have a lot of close friends
Friends who treat me nice and sweet
Friends that I spend time with
And who I love
When I'm at UNCG
I like to go to Bojangles on campus
In the EUC and the library too
When I am not at UNCG
I like to go to Starbuck's
Target
Friendly center
I go to Daystar church
It is important to me because of my faith

And because all of the people there
are friendly
treat me nice and sweet

One of my goals used to be to graduate from the program

But now I have

I am a UNCG alumnus

I am very proud of that

I was doing volunteering and an internship

but I wanted a paying job

A job that pays money

And now I have one

A job that gives me something to do

that makes me feel great

that makes me feel important

I like being independent

Living on my own

Making my own choices

In the future, I want to get married and have a family

But I am not focused on that right now

Right now I am focused on my two jobs

being independent

and living the life

that I love

My Life

By JOE

I just liked it
where I'm living
I just liked it
I guess I liked
the atmosphere of it
plus I wanted to be farther off campus
so I could not be as close
to school.

I want to be
A drug and alcohol counselor
Yeah, that's what I want to be
cause my brother is an alcoholic
and so is my aunt
and my uncles
so I've lived with it
And had to live with one of them
so I know what it's like
not to have
like a brother
that's why I want the kids to know enough
that's why I want....that's why I picked that.

And then
I know next semester
I'm taking the Intro to Social Work
I mean, they all
they advocate for people
when people like feel down
I guess I help them with that.
So,
that's kind of similar,
I met a lot of people that go here that like
look up to me
which is kind of good
but it's kind of scary
at the same time
It's a big responsibility
but..

I guess from who I am
they see that
my cerebral palsy and stuff
they see that
I mean, they treat us differently
because they
they see who I am
and then automatically
they assume
 that I'm gonna act a certain way.
I guess that's probably because they don't know
if they don't have it
they wouldn't know.

I've noticed when I get to know them
they start to realize that I'm not,
that I don't act like that
but I think that's just cause they don't know.
that's what a lot of my friends have told me
that don't have disabilities
is they don't really know what it is.
Yeah.
So they would know what it is
more equality I guess.

I make decisions about my time

I use
the Heat
and the GTA
and all that.
I go to Jake's
cause they have tacos
And they're cheap.
And then the cafe and the EUC
And then..
I go to Greene Street sometimes.
 play pool
I go to my friends' dorms sometimes too.
Which is cool cause I can get
I can see what it looks like
it's kind of cool for me to see it.

I hang out with friends outside of the program too.
a lot
I spend time with people that I think are mature
and hold themselves well.
It's just like
the way you hold yourself.
someone who sticks up for you
and shows a type of sympathy toward you.
if someone's bullying you or whatever,
they can stick up and say something.
and they go out places with you.

I'm a disability advocate
I guess that would be the right word
I'm a student.
I'm a YouTuber
I'm a brother.
I like helping people
people have told me that I inspire them
so that's..
that's cool
getting my license was an achievement
Cause people told me I couldn't
so getting it was nice
I pushed myself to get it
graduating high school was an achievement
getting into college was an achievement
cause people told me that I couldn't get in.

Something I haven't been able to do yet
Is the degree,
we're still getting a certificate
I'm alright with that.
I mean if we could, yeah.
If it could happen
Yeah
it's not as big of a deal for me,
but if it could happen,
I'd be okay
It takes hard work.
keep pushing and don't give up on it.
And then I would just say ignore
the people that tell you
you can't.

I feel like I'm treated good
like staff are informed
are more informed then they were
before
getting to know our strengths and weaknesses
not saying
you're just like the rest of them.

Going home is
Weird.
Different
Not the same
Awkward
when I go home I don't really do anything and I just get really bored
and it's just different
cause I'm so used to doing stuff all the time.
then when I go home it gets really
boring.

If you want to be respected
You have to respect others
and I have
I have disability rights
freedom of speech.
right to education.
right to be innocent until proven guilty
freedom from slavery.
the freedom to equality
cause I have a disability,
so that's the most important to me.
well
obviously the slavery too
cause I don't want..
I do not want to be a slave.

I feel like everybody's rights gets stepped on sometimes.
I feel like everybody,
I mean everybody feels like that.
but it's nothing like,
like that's unbearable.
but you should tell them.
voice your opinion and then if it doesn't work
you can call somebody

and see what is wrong
and then get them to talk to them
and get the person to talk to them.

College

It's a new beginning.
it teaches you skills.
life skills to live on your own.
you gotta pretty much do everything on your own
or else
you can't eat
it's gotten me more friends.
it's matured me more.
I've been thankful for what I have since I've been away from it
like my parents and stuff.
cause now that I'm away from it,
it's different from when I was seeing them everyday.
I got more out of my shell I guess.
I got more involved.
so it's independence
it teaches you independence.
its me doing the work
it can't get done without me

I had a chance

By DOLPHIN

I think
this program
it's been good
it teaches me more
more about independence
independence in learning new things
I have the right
sometimes
I have the right
the right
I have the right
to speak my mind
to speak my mind about my feelings
to speak my mind about what I know
to go anywhere I want to
to take charge
to keep it as it is
I only let friends and family
have my number
you know
if they want to share it with somebody else
they ask me
they ask me
they ask me first
its my choice
its my choice to pick my path
to choose what I want to do in life
I do it on my own
I teach myself
I teach myself about routines
I have support
I ask for support
when I need it
I'm a bookworm
I go to the library
the teaching resource center
have my own library card
for checking out books
I volunteer at the library
see the young kids coming in

and help with morning reading
I meet new people
in UNCG classes
and peer companions
peace and conflict studies
African American studies
People with disabilities in American Society
No,
I can't think of any places
that I can't go
I have two places
I want to live
NC or Richmond
I want to be a counselor
for young kids
or people with disabilities
I want a partner
and a family
I feel respected
when people see me
for who I am
some girls can be a tomboy
I feel respected
because I help out
I help with the community
I didn't used to be in front of people
but now
I get in front of people
because I had a chance
I had a chance
to help

APPENDIX D

MODIFIED CONSENT FORM

Project Title: Why College Matters: Student directed/community engaged process of credential development for postsecondary education certificate for students with Intellectual Disabilities

Co-Investigators: Lalenja Harrington, M.A., Dr. Carl Lashley, Kim Miller, M.A.

Participant's Name: _____

What is the study about?



It highlights the student perspective on personal outcomes as impacted by participation in a 4-year university certificate program.



It includes a community engaged approach,






interviews with individual students and a review of student's goals and life plans.



Why are you asking me?

You have been asked to participate in this study because you are a student in the ICS program. You must be 18 or older to participate.

You are a  student and you are 

 **UNC**
Beyond Academics

What will you ask me to do if I agree to be in the study?

We will ask you to do the following:

- 1 Complete a Personal Outcome Measures interview



OR

give us permission to review a transcript of your interview if you have already had one this year



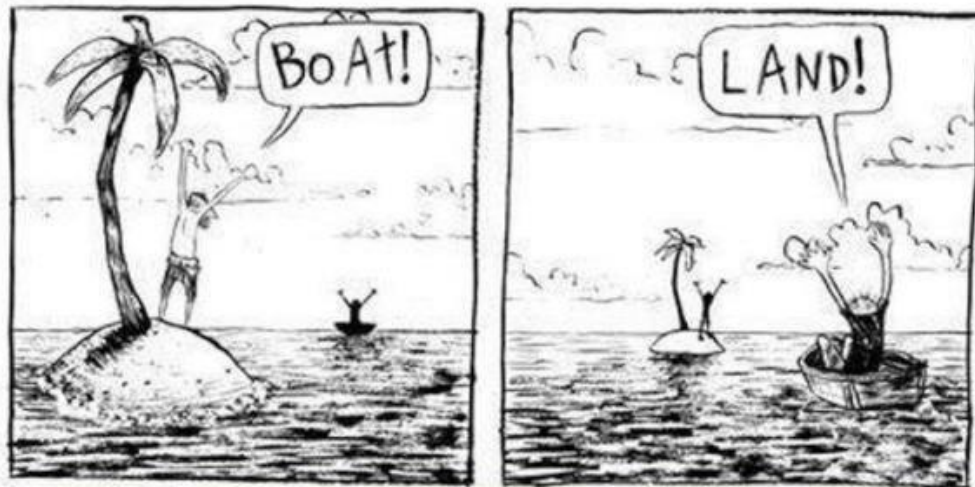
(the interview will take approximately 1-1.5 hours and you will be asked questions about yourself and about your thoughts on personal outcomes in your life)

- 2 Share the following documents that outline your goals in life for analysis



1. **Senior Portfolio**
2. **Person Centered Plans developed in your PATH and CIRCLES planning classes**
3. **College support plans developed with your advisor**
4. **Presentations that you have made related to your goals in college**
5. **ICS interview forms, application and intake forms**

3 Provide feedback about interviews and analysis to ensure that your perspective is accurately reflected



Perspective...

Are there any audio/video recording?

Yes, there are audio recordings involved. Your voice may be recognizable on the recording, but it will be stored in a safe place and we will keep your recording confidential.



What are the dangers to me?



If any question on the survey makes you feel uncomfortable or sad, you may choose to skip the question.

QUESTIONS, SUGGESTIONS, WANT MORE INFORMATION????



Lalenja Harrington at (336) 324-0795 (or l_harrin@uncg.edu),

or

Dr. Leila Villaverde at (336) 334-2475 (or levillav@uncg.edu).

CONCERNS ABOUT RIGHTS OR RISKS OF PROJECT????

Office of Research Integrity at UNCG toll-free at
(855)-251-2351.

**Are there any benefits to me for taking
part in this research study?**



Nothing beyond helping us understand how being in the ICS program and college impacts your life. We will share the results of the study with you if you decide to participate.



Are there any benefits to society as a result of me taking part in this research?

Your feedback can improve our program and also educate others, nationally and internationally about the impact of college.



Will I get paid for being in the study? Will it cost me anything?

You will not get paid for your participation in this study. It will not cost you anything to participate in this project.



How will you keep my information confidential?

We will do several things to keep your information confidential during the study:



You will be assigned a false name during the interview process. This same name will be used on all other documents.

All data will be kept in a locked file cabinet in a locked office on the UNCG campus.

The master list of participant's names and their assigned false names will be kept in a separate locked file cabinet in a locked office on the UNCG campus.



The information from the interviews will be entered into a computer.

- These computer files will be password protected and stored on the secure UNCG server.
- Computer files will not have identifiable information (e.g., your name or personal information)

All information gathered in this study is strictly confidential unless we are required by law to share it with authorities.



What if I want to leave the study?



You have the right to decide NOT to participate. If you decide to participate, you can change your mind and stop participating at any time. If you do not want to participate or stop participating it will not hurt you in any way. **You will stay in the ICS program and your support services will not be changed.** If you choose to stop participating, you may ask that any information about you that we have collected be destroyed unless it is in a de-identifiable state (i.e., my name and personal information are not on it).

What about new information/changes in the study?



If important new information about this study becomes available which may change how you feel about participating, this information will be provided to you.

Voluntary Consent by Participant:

By signing this consent form you are agreeing that you have read it, or it has been read to you, and you fully understand the contents of this document and are openly willing to consent to take part in this study. All of your questions concerning this study have been answered. By signing this form, you are agreeing that you are 18 years of age or older and are agreeing to participate.

Signature: _____ Date: _____