

A CRITICAL STUDY OF EXPERIENCES AND BELIEFS OF ADMINISTRATORS  
OF INCLUSIVE POSTSECONDARY EDUCATION FOR STUDENTS WITH  
INTELLECTUAL AND DEVELOPMENTAL DISABILITY

by

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## **DEDICATION**

I dedicate this work to:

My family,

Sam, Kaye, Aaron & Synda, Cohen, Kallie,

Nina, and Ruby Love,

for whom I strive to set a good example

My Mom,

Who gave me roots and wings

Phil,

The perfect branch for this butterfly

And God,

My spiritual Thou

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## **LIST OF ABBREVIATIONS**

<b>Abbreviation</b>	<b>Description</b>
<b>AAIDD</b>	American Association on Intellectual and Developmental Disabilities
<b>ADA</b>	Americans with Disabilities Act (1990)
<b>CRPD</b>	Convention on the Rights of Persons with Disabilities
<b>CTP</b>	Comprehensive Transition Program
<b>DE</b>	Developmental education
<b>EHS</b>	Education for All Handicapped Students
<b>HEOA</b>	Higher Education Opportunity Act (2008)
<b>HLC</b>	Higher Learning Commission
<b>ID/DD</b>	Intellectual disability and developmental disability
<b>IDEA</b>	Individuals with Disabilities Education Act (2004)
<b>ODS</b>	Office of Disability Services
<b>PSE</b>	Postsecondary education
<b>TPSIDS.</b>	Transition Postsecondary Programs for Students with Intellectual Disability

## **ABSTRACT**

In this study, naturalistic qualitative inquiry grounded in the constructivist paradigm (Erlandson et al., 1993; Guba & Lincoln, 1989; Lincoln & Guba, 1985) and a critical lens informed by the educational philosophy of Paulo Freire (1970/2013) were used to examine the experiences and beliefs of administrators of inclusive postsecondary education programs designed for students with intellectual and developmental disabilities (ID/DD). I contextualized the study within research from the fields of inclusive postsecondary education for students with ID/DD, developmental education, K–12 special education administrators, and social justice in education, with broader contextualization in disability studies and human rights.

Using constructivist and critical lenses for data analysis, I discovered findings within and across the cases. Within case findings indicated that varying types of marginalized experiences such as disability and diversity impact administrator practices. Findings across all nine participants led to the construction of a definition of administrator beliefs, and to an understanding of administrators knowledge of the oppressions that students with ID/DD face throughout their lifetime. Administrator's exposure to principles of equity, access, social justice, and critical perspectives in education also helped them facilitate inclusive PSE.

Results from the study suggest that beliefs, which include knowledge of students' growth and development potential and knowledge of student oppressions, are key components of administrator's work and that these may be acquired through many kinds

of personal, professional, and educational experiences. Additionally, regardless of experiences, cultural and critical education studies can foster a critical understanding of the student population, particularly through the practice of critical self-reflection.

Implications are that college students with ID/DD should be considered a marginalized student group and that their population be added to other student groups when considering culturally relevant research and instruction in social justice, critical studies, cultural foundations of education, and deficit thinking. This suggestion also extends to considering the distinct instructional needs of students with ID/DD as well as their support needs. Many of these issues have already been explored within the inclusive PSE niche. My recommendation is that higher education begin to take an inclusive stance to welcome and support this new college student population.

## **I. INTRODUCTION**

### **Introduction to the Study**

*Given the longstanding struggle for equality experienced by people who differ only in terms of sociocultural or racial factors, it is not surprising that the relatively recent struggle for equal access to society's benefits (inclusion) by people with physical, intellectual, and developmental differences is understudied, daunting, and sometimes controversial. Additionally, the obvious fact that ability and developmental diversity exists in tandem with sociocultural and racial differences adds further complexity.*

(Lang, 2017, p. viii)

Throughout the history of the United States, evolving social, political, and economic conditions have repeatedly impacted the content, purpose, and delivery of postsecondary education (PSE) as well as access to it for diverse student populations such as women and minorities (Cahalan et al., 2019; Smith, 1990). Currently, a new move toward increasing inclusion in higher education is focusing on students with intellectual and developmental disabilities (ID/DD). This student population brings with it a shift in the conceptualization of higher education placing a greater focus on the social benefits of access and inclusion and on the benefits of incremental academic growth as opposed to the achievement of rigid course requirements and the use of rigid methods of course delivery. The inclusion of students with ID/DD in PSE stretches the conceptualization of PSE beyond its traditional boundaries considering access to education as a basic human right, particularly education in locations that are socially valued, inclusive, and provided across the lifespan. Such inclusion aligns with the Universal Declaration of Human Rights (U. N. General Assembly, 1948) for individuals with disabilities, as well as

current discussions in higher education considering alternative methods of assessment and flexible learning outcomes (Alexander, 2010; Cahalan & Perna, 2015).

Students with ID/DD are coming to college today in greater numbers than ever before in programs designed specifically to provide support and guidance for them through inclusive PSE experiences (Grigal, Hart, & Weir, 2012; McEathron et al., 2013; Thoma, 2013). One hallmark of these programs is a more personalized integration of student supports designed around highly individualistic student needs (Hart & Werbach, 2020). The field of developmental education (DE) has long studied and responded to the support needs of underprepared or marginalized college students with a host of programs and services. These programs and services include the provision of supplemental instruction designed to address the specific needs of disadvantaged students (Yue, et al., 2018), the integration of learning communities in DE math and English classrooms (Baier et al., 2019), the promotion of learning frameworks courses (Hodges, et al., 2019), and also includes responding to the support needs of students with learning disorders (Troiano et al., 2010) and other disabilities (Higbee, 2003; Knox et al., 2000; Schutz, 2002). Higbee (2003) stated “in inclusive institutions of higher education, no student should be an afterthought” (p. 1). This emerging college student population, students with ID/DD; however, have not yet been included in DE conversations and research, nor is it evident that their presence has been noted by DE practitioners although administrators of inclusive PSE programs for students with ID/DD are well aware of their presence and their participation in DE courses (S. Moraska, personal communication, September 2017).



## **Introduction to the Inclusive PSE Movement**

The emerging movement toward inclusive PSE for students with ID/DD is the result of years of grassroots advocacy undertaken by concerned stakeholders such as parents and educators (Thoma, 2013). Recently, the movement gained federal legislative and funding support through the Higher Education Opportunity Act (HEOA) of 2008 (Gamel-McCormick, 2016; Hardy & Woodcock, 2015). Federal and localized advances have occurred in tandem with shifting societal attitudes regarding the capabilities of individuals with ID/DD as well as shifts from deficit models of disability to environmental and diversity models, which transfer the “problem” of disability from the individual (deficit/internal) to the environment and society (external/context). This ideological shift places the onus for providing appropriate PSE services for students with ID/DD on educators and institutions. It should be remembered, however, that access to higher education for new populations and shifts in programming to meet their needs is not a new occurrence; the history of PSE is rife with examples including the influx of women, military personnel, students of color, and other racial and ethnic minorities (Casazza, 1999; Musu-Gillette et al., 2016; Payne et al., 2017; Smith, 1990; Thompson, 1988).

The reauthorization of the HEOA in 2008 established students with intellectual disabilities as a distinct college student population (Higher Education Opportunity Act, 2008). This legislation outlined specifications with which inclusive PSE programs can be evaluated in order to receive the comprehensive transition program (CTP) designation. In addition to setting program standards, another benefit of achieving the CTP designation is

that students enrolled in CTP programs are eligible to receive federal student financial aid such as Pell grants and work study, making higher education accessible to a greater number of individuals with ID/DD (Madaus et al., 2012). Programs achieving CTP status must provide individual support where needed and focus on the inclusion of students with ID/DD in a full range of campus activities, both social and academic. Vocational training and support are also requirements for CTP programs and program outcomes include a broader range of outcomes than traditional college degrees including certificates and apprenticeships (Madaus et al., 2012).

The HEOA defines a college student with an intellectual disability as a student with mental retardation or a cognitive impairment, characterized by significant limitations in intellectual and cognitive function 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 under the Individuals with Disabilities Education Act (IDEA) (Individuals with Disabilities Education Act of 1990, 2004). Although students with ID/DD are the least likely of all students, including those with other types of disabilities, to enroll in any type of PSE within four years of exiting high school (Hart & Werbach, 2020; Newman et al., 2009), they can benefit academically, vocationally, and socially from opportunities to participate in higher education just like other college students (Butler et al., 2016; Gilmore & Cuskelly, 2014; Hove et al., 2016). Furthermore, attending college with their broader peer group has the additional benefit of lowering stigma and increasing social inclusion for them (Uditsky & Hughson, 2006). Given that individuals with ID/DD are the most highly stigmatized and vulnerable of all population groups, including those with other types of disabilities, this benefit cannot

easily be overlooked (Ali et al., 2016; Butler et al., 2016; Ditchman et al., 2013; Fisher et al., 2013).

Just like other college students, students with ID/DD may require academic and social supports to access the benefits of higher education in an equitable manner. Indeed, CTPs focus very much on facilitating inclusion and creating appropriate supports on college campuses to integrate students with ID/DD into all of campus life while not drawing attention to their differences. Such integration and support for students with ID/DD provides an avenue for postsecondary inclusion and access to opportunities for growth and development in socially valued locations among their peers.

### **Educational Equity and Developmental Education**

The inclusion of diverse populations is frequently addressed by institutional mission statements and evidence of diversity is often a requirement in the institutional accreditation process (Higher Learning Commission, 2017). Although open-door policies at community colleges allow any student the right to enroll and thus enable institutions to avoid discriminatory practices, research shows that access does not always ensure success and completion (Dougherty et al., 2017). In response to an influx of under-prepared college students either through open-door policies or diversity initiatives, institutions of higher education have long sought ways to increase educational equity by addressing the academic and social support needs of nontraditional, marginalized, and diverse groups of students (Arendale, 2002, 2006; Stahl & King, 2008; Tinto, 2006).

The field of developmental education (DE) evolved in response to college student support needs and recognizes that many individuals, for any number of reasons, may come to college underprepared for college-level coursework. DE is a field dedicated to

research, policy, and practices that focus on multiple dimensions of student supports, including course- and non-course-based supports (King et al., 2017). DE research examines student demographics—data on cultural and social groups, veterans, women, minorities, first-generation students, and students from low socioeconomic backgrounds (Acevedo-Gil et al., 2015; Hurtado et al., 2012)—and it extends further to include factors that contribute to students’ social and academic growth, such as cognition, affect, identity, sense of belonging, personal growth and development, study skills, self-regulation, and motivation (Fong et al., 2018; Hurtado & Carter, 1997; Pascarella, 2006; Perry, 1999; Tinto, 1997; Torres et al., 2009). DE also considers disciplinary specific research that supports student learning including integrated reading and writing (Pierce, 2017), developmental math delivery (Weisburst et al., 2017), disciplinary literacy (Shanahan & Shanahan, 2008) and contextualized learning (Perin, 2011). Ultimately, the purpose of such research is to inform curriculum and pedagogy to provide better support for students and increase students’ academic success and retention.

DE’s mission is grounded in an ideology based on the belief that human growth and development occur throughout the lifespan with foundations embedded in social justice and educational equity (Alexander, 2010; Hytten & Bettez, 2011). The term developmental may be contrasted with the term remediation, which carries with it the connotation that students have deficits that need to be fixed (Higbee, 1996). Instead, DE focuses on students as humans who experience natural growth and development across the lifespan (Piaget, 1952) and who may not have achieved college readiness for any number of reasons; internal and external. The field officially adopted the name developmental education to emphasize its roots in developmental psychology and to

focus on the promotion of “cognitive and affective growth of all postsecondary learners at all levels of the learning continuum” (Arendale, 2007, p. 18).

The emerging field of inclusive PSE for students with ID/DD shares the same foundational beliefs. Both ID/DD and DE recognize a full spectrum of intellectual abilities and differing rates of growth and development, as well as the value of access to educational opportunities to support the growth and development of individual student strengths and talents. Unlike the field of DE, however, the field of inclusive PSE for students with ID/DD does not have a long history with many iterations, and the rights of students with ID/DD to attend college with their broader peer group have not been firmly established or supported historically, socially, or culturally (Grigal & Hart, 2012). The inclusive PSE movement pushes past prior limited opportunities for the lifelong growth and development of individuals with ID/DD.

Both DE and inclusive PSE for students with ID/DD take a holistic approach to supporting students, recognizing that effective programs for diverse student populations should understand and respect diversity, deconstruct assumptions, eradicate stereotypes, explore critical pedagogy and implement new ways of teaching, expand definitions of scholarship, focus on assets rather than deficits, provide peer support, and foster inclusivity (Bruch & Higbee, 2002; Higbee & Goff, 2008). Both fields offer multifaceted supports provided inside and outside the classroom (e.g., tutoring, supplemental instruction, and advising; Griffin et al, 2016; Raynor et al., 2016).

The field of DE shares concerns for underprepared students with other campus sources of support (e.g., student affairs, academic advising, and TRIO programs), and it incorporates instructional practices that bridge disciplines, including first-year seminars,

co-requisite courses, contextualized learning, and learning communities (Moreno, 2014). The same can be said of the field of inclusive PSE; however, inclusive PSE is designed to penetrate all existing campus systems and change mindsets so that individuals with ID/DD can be accepted into the social fabric of campus life rather than be served by separate, pull-out programs which may also have entrance criteria based upon test scores. Although they are referred to as programs, the main feature of an inclusive PSE program is the provision of a nearly invisible structure supporting students with ID/DD within main programs on campuses.

Unlike students from minority and marginalized groups who are encouraged to attend college through programs such as TRIO, Upward Bound, and Gear Up, students with ID/DD do not receive the same encouragement. Many students with ID/DD end up in vocational or community programs and, although transition laws support students' taking more leadership in their PSE planning, only a small number do so (Shogren & Plotner, 2012). Because it has not become normalized, the establishment of inclusive PSE programs for students with ID/DD extends from grassroots and community efforts reaching out to interested higher education partners who work together to gather resources from a variety of locations with the common goal of creating equitable PSE opportunities for students with ID/DD (Baker et al., 2018). Because the establishment of inclusive PSE serves to remove educational barriers for a marginalized group, the work of those engineering inclusive PSE opportunities on college campuses for students with ID/DD can be viewed as advocacy work. Individuals who are involved in this work are agents of change interrupting a cycle of oppression for a student population who currently lack the skill set to interrupt the cycle for themselves (Harro, 2013).

## **Marginalization and Intellectual and Developmental Disability**

Individuals with ID/DD have traditionally been excluded from higher education as an extension of their exclusion from participation in society in general. They constitute a group who, because of their vulnerability and lack of self-advocacy skills have been subjected to greater, more pervasive marginalization, stigma, and abuse than have all other disability populations (Ali et al., 2016; Fisher et al., 2013; Koh, 2004; 2010; Scior, 2011). Prior to the 1970s, public policy supported the forced institutionalization of individuals with ID/DD, frequently in appalling conditions and including involuntary (forced) sterilization. A philosophy of eugenics was also embraced by the public before policy changes in the 1970s (Nerney et al., 2017; Rowlands & Amy, 2018).

The rights of individuals with ID/DD have lagged behind the rights of all other Americans including those with all other types of disabilities, who experienced their own civil rights movement in the 1970s on the tail of the 1950s Civil Rights movement (Spaulding & Pratt, 2015). It was not until 1999 that Justice Ginsberg ruled that individuals with ID/DD have the right to live in the community rather than in institutions and the law expanded disability rights to include the integration of people with disabilities into “the fabric of community life” (*Olmstead v. L.C.*; as cited in Bagenstos, 2004, p. 55). Less than 20 years after this decision, students with intellectual disability and their advocates are now finding ways to extend these rights to include participation in college; however, in doing so, they advocate for a population whose identity has been inextricably impacted by ostracizing and negative social, cultural, and historical treatment.

Like students from other marginalized groups, students with ID/DD have had little opportunity to develop their identities as free agents in a democratic society and to experience identity development free from external oppressions. Tatum (2013) stated that identity development comes not just from internal factors but is also derived from noting “who the world around me says I am” (p. 6). Thus, individuals who are perpetually excluded from partaking in the benefits of society may also identify themselves as not being worthy or capable of experiencing those benefits. Such “internalization” of marginalized experiences can contribute to, among other things, low self-esteem, stress, hopelessness, disempowerment, and mistrust (Harro, 2013). Young (2013) summarized the impact of internalization stating; “all oppressed people suffer some inhibition of their ability to develop and exercise their capacities and express their needs, thoughts, and feelings” (p. 35). Thus, experiences such as being diagnosed as “below normal” and being excluded from the typical classroom and placed in “special education,” situations which may have a positive side as well, simultaneously contribute to student characteristics and conditions that students with ID/DD bring with them to college campuses.

### **Inclusive Postsecondary Education Programs**

Inclusive PSE for students with ID/DD sits at a complex intersection in higher education by continuing the work of legally mandated K–12 free and appropriate public education (Individuals with Disabilities Education Act, 2004) into a non-mandated realm. The inclusion of students with ID/DD in college challenges notions of who should have access to higher education, what types of educational experience should be considered rigorous, what the purpose of higher education is, and whom it should serve. It challenges



the idea that IQ and entrance skill levels and educational credentials are the criteria for eligibility to attend college and that academic rigor identified through traditional modes of representation such as reading and writing are the hallmark of a college education and career preparation. Inclusive PSE focuses instead on equalizing opportunities and providing educational equity to a group of traditionally marginalized and excluded students who can and do benefit from such inclusion indicating the social justice nature of this education initiative. “The goal of social justice” according to Bell, 2013, “is full and equal participation of all groups in a society that is mutually shaped to meet their needs” (p. 21).

Inclusive PSE seeks to embed high-touch, infused and integrated services throughout the college experience and to consider all aspects of the student’s experience to be equally important (Hart & Werbach, 2020). For students who have frequently been marginalized in the K–12 system and subjected to bullying and victimization (Hartley et al., 2015), inclusion with neurotypical students (students without disabilities) provides optimal growth situations and a chance to develop meaningful relationships in a new life apart from their K–12 experiences (Ryan et al., 2017). Students with ID/DD also benefit academically and vocationally from inclusive programs (Van Haneghan, 2012).

Although a growing body of research on the benefits of inclusive PSE for students with ID/DD exists, most research on program implementation has been descriptive due to the unique settings in which each program developed through relationships established between parents, local school districts, local colleges, and service providers. Much research is also practitioner based for the same reason, with practitioners sharing knowledge of their individual experiences through publications dedicated to the

movement such as Think College and AHEAD (the Association of Higher Education and Disability). Recently, empirical studies focusing on program implementation have begun analyzing steps in program implementation from multiple programs and begun to develop lists of suggested steps for program implementation such as gathering resources and finding allies on campuses (Baker et al., 2018; Francis, et al., 2018). Lacking in the literature on inclusive PSE programs implementation are empirical studies examining the experiences and beliefs of the professionals who serve the role of program design, implementation, and facilitation. In this study, I refer to these individuals as program administrators.

### **Administrators of Inclusive PSE**

Administrators of inclusive PSE are the university personnel, typically a faculty member or members, who assess university and community needs; assemble partners and program materials such as personnel, funding, and space; and create or sustain collaborative relationships including student supports, program content, outcomes, and evaluation. Administrators' work includes a high level of advocacy and collaboration not normally seen in other higher education roles (Smith & Will, 2010) and involves a novel, understudied student population. Elks et al. (2019) noted that individuals wishing to begin inclusive postsecondary education programs must have a mix of passion and organizational strategies in order to succeed in creating inclusive programs.

In their unique role, administrators occupy a place at an educational crossroad, performing work that is both practical and critical. Administrators and inclusive PSE programs extend the current boundaries of higher education. They work with irregular funding sources in non-standardized locations, and their task involves gaining support

and establishing relationships with other administrators, faculty, and staff on their campuses as well as with community organizations with whom they may partner to receive publicly funded services or establish work and internship opportunities for their students. Administrators also reach out to families seeking postsecondary opportunities for their students with ID/DD and to schools, to inform them of postsecondary options for students and to work with them to prepare transition plans.

The work of administrators contains a strong advocacy component. Kavulic (2017) noted that the successful implementation of a transition or PSE program is the result of considerable effort on the part of program staff and organizers who gain support through strong, persuasive stories, and he has questioned whether such programs will continue after the elimination of initial funding unless they are integrated into existing campus systems. Many campuses are not prepared to integrate this new population fully (Getzel, 2008; Plotner & Marshall, 2015) and integration is less likely when separate policies are created for students with ID/DD (Grigal et al., 2014). Even after a program is established, conversations and advocacy are ongoing. Paiewonsky et al. (2013) noted that “the work of explaining and promoting an inclusive postsecondary program is never really over. Each time new staff or deans are hired, you will again be asked to explain the model, describe typical student experiences, and share outcomes” (p. 4).

The advocacy nature of their role indicates that administrators serve a critical function. The question then becomes: What is that function and how do administrators prepare for it? To examine this question, I used a critical framework informed by the educational philosophy of Paulo Freire. According to Freire (1970/2013), educators must have a deep understanding of the problems that they study; they must recognize that

problems of oppression are usually seated in multiple, sometimes obscured, layers that represent many factors. This is certainly the case for students with ID/DD, who have suffered a long history of abuse, neglect, and marginalization (Nerney et al., 2017).

Although great legal strides and practical work have led to the proliferation of programs across the U.S., inclusive PSE is still a new concept for many, and information sharing, such as that provided in scholarly research is a key to advancing its movement (Miller et al., 2018).

While scant research is available exploring the experiences and beliefs of administrators of inclusive PSE programs, there is a body of research exploring the experiences and beliefs of K–12 special education administrators. This body of research indicates that experiences and beliefs do have an impact on administrator’s facilitation of inclusive education for students with disabilities in their districts. Opportunities to interact with students with disabilities allow administrators to witness the growth and development of students with disabilities which creates a cognitive shift in their perception of students’ capabilities, and shapes and changes attitudes prompting administrators to look for educational opportunities that promote the growth and development of students with disabilities such as increasing inclusion with non-disabled students (Allan, 2016; Jacobs-Bell, 2014; Praisner, 2003; Templeton, 2017; Vasquez, 2010). This study extends the research on K–12 special education administrators into the higher education realm with further contextualization within social, legal, and historical contexts that surround the integration of individuals with ID/DD into community and educational life.

### **Problem Statement**

Therefore, unlike K–12 special education administrators, the work of administrators of inclusive PSE is not done in response to legal mandates, nor do colleges typically have a place already prepared on campuses for students with ID/DD or policies inviting them to campus. Although K–12 special education administrators are motivated by the law, research indicates that their experiences with students with disabilities and their beliefs about their growth and development potential impacts their implementation of inclusive education for students with disabilities in their schools (Templeton, 2017); however, research on the experiences and beliefs of administrators of inclusive PSE for students with ID/DD at the postsecondary level and how it impacts their implementation of inclusive education is missing from the literature on inclusion in postsecondary education. Therefore, to address this gap in the literature, the following study addressed the following research questions.

### **Research Questions**

Overarching RQ: How do the personal, professional, and educational experiences of administrators of PSE programs for students with ID/DD and their beliefs about the human growth and development potential of students with ID/DD impact their work in the field of inclusive PSE?

RQa: What are the personal, professional, and educational experiences of administrators of inclusive PSE programs for students with ID/DD?

RQb: What do administrators believe about the human growth and development potential of students with ID/DD?

RQc: How do those experiences and beliefs impact administrators' work in the field of inclusive PSE?

### **Assumptions**

My assumptions going into the study were that administrators of inclusive PSE programs came to their roles having had prior experience with individuals with ID/DD. I also assumed that these prior experiences helped prepare them in some way to want to fulfill their positions and promote the inclusive higher education for students with ID/DD agenda.

### **Conceptual Framework**

Given that individuals with ID/DD are a highly stigmatized and marginalized population, and the movement to include them in higher education is primarily driven by stakeholder advocacy (i.e. parents and special educators), for this study I used a critical conceptual framework to explore the experiences and beliefs of administrators of inclusive PSEs for students with ID/DD. My conceptual framework is based upon the educational philosophy of Freire which proposes an educational process based upon questioning, or "problem-posing," rather than "the banking method." Problem-posing education creates novel paths to learning as answers are sought by different people exploring their local situations by considering the surrounding historical, social, economic, and political systems looking for imbalances of power. This is contrasted with the banking method of education in which pre-packaged educational content, including pre-determined thoughts and opinions, is used to disseminate information and knowledge in an authoritarian and controlled manner, and individual perspectives and knowledge is not seen as legitimate information (Freire, 1970/2013).

The following aspects of Freire's educational philosophy served as primary scaffolding for the study: (a) Freire's insistence that all humans can grow and develop, and that any education which prohibits this growth and development should be considered dehumanizing, (b) Freire's encouragement for educators and their students to examine their local contexts and discover systemic oppressions which prohibit humanizing practices from taking place, and (c) educators of people with ID/DD as advocates working in solidarity to promote inclusive, humanizing educational opportunities for people with ID/DD across their life span.

### **Research Design**

The research design for the study is a naturalistic case-study (Skipper et al., 1993; Guba & Lincoln, 1989; Lincoln & Guba, 1985). Participants were nine administrators of inclusive PSE programs from different types of institutions and geographic locations in the United States. Data was collected using a series of three–sixty minute interviews (Seidman, 2006) in which the first two interviews collected personal and program information, and the third focused on deeper reflection of administrator experiences. Data analysis was continuous from the beginning of data collection (Glaser, 1965) and utilized several types of analysis including a priori coding and in vivo coding (Miles et al., 2014). Themes were developed within cases and across cases. Thematic development within cases led to the construction of individual narratives in which the interconnectedness of individual experiences and beliefs were connected with inclusive practices facilitating inclusive PSE. Cross-case analysis enabled the discovery of additional themes. These themes included the use of knowledge and attitudes to construct a definition of the concept of beliefs, administrator's knowledge of external and internal student

oppressions, the role of conscientization (critical self-reflection) in administrators understanding oppressions, and the role that critical or social justice education had in helping to build a critical understanding of systemic student oppressions and developing a critical language with which to label such oppressions.

### **Significance of the Study**

This study is significant because it applied a critical lens to the topic considering access and equity to higher education for students with ID/DD in a social justice and human rights context, highlighting the advocacy element of the administrator's role. The study also connected administrator knowledge of the population they serve to their willingness to advocate, connecting administrator knowledge with effectiveness. This study is also significant because it has the potential to contribute to the development of administrator competencies in a newly evolving administrative higher education role.

### **Organization of the Study**

The study is presented in five chapters. The first chapter, the introduction, lays the foundation for the study and includes the research questions and conceptual framework that guides data collection and analysis. Chapter two, the literature review, broadly introduces the reader to facets of inequities that individuals with ID/DD encounter, emphasizing the importance of the inclusive education movement. Chapter three presents methods for data collection and analysis. Chapter four presents findings in three sections beginning with an introduction of four emergent themes, followed by three focus cases, and concluding with a cross-case analysis of all the participants. Chapter five presents discussion, implications, and recommendations for future studies.



## **Definition of Terms**

The following terms are defined for the benefit of those not familiar with certain terms that are associated with critical studies, disability law and disability studies, as well as the inclusive PSE movement which is a natural outgrowth of K–12 special education transition mandates.

**Agency**, for individuals with ID/DD, refers to developing the skills needed to direct one's own life, given personal skills and desires. This includes three primary components: developing self-advocacy and self-determination skills; understanding one's self well enough to understand personal resources or limitations, as well as determining personal goals; access to education and supports that promote the development of self-determination and understanding one's self (Wehmeyer et al., 2017).

**Americans with Disabilities Act of 1990** is legislation which provides individuals with disabilities the right to live independently in one's community of birth or choice.

**Comprehensive transition program (CTP)** is the name given to PSE programs that support students with ID/DD who seek to continue academic, career and technical, and independent living instruction at an institution of higher education in order to prepare for gainful employment and which comply with standards set by the HEOA, 2008. One of the biggest benefits of this designation is that students with ID can access federal student aid to attend CTP programs.

Standards include the following: courses must (a) be offered by a college or career school that is approved by the U.S. Department of Education, (b) be designed to support students with intellectual disabilities who wish to continue

academic, career, and independent living instruction, (c) offer academic advising and a structured curriculum, and (d) ensure that students with ID participate at least 50% of the time in classes (credit or not-credit) with nondisabled individuals (Grigal, Hart, & Weir, 2012).

**Disability studies**, in contrast with studies of disability or in disability-related fields such as occupational therapy, physical therapy, and others, seek not to do research on the person with disability, but to bring forth the voice and viewpoint of the person with disability. Disability studies are seen as empowering and emancipatory, and include many disciplines, such as architecture, journalism, film, philosophy, policy, art, choreography, literature, poetry, history, anthropology, sociology, and law (Kanter, 2013).

**Disability models** include the minority-group model of disability which views people with disabilities as oppressed and disadvantaged and comes from a rights-based standpoint. A limitation of this model is that securing rights and privileges for individuals who are disabled does nothing to eradicate environmental and cultural barriers. A second disability model is the social model of disability which sees disability as socially constructed and places the onus of adaptability on society (removing barriers). This model raises questions of identity and individual experience of disability. A third disability model is the cultural model of disability which is related to the social model of disability with the addition of critical and postmodern theory, and places disability along with other identities and as a shifting state. Ware, 2001, as cited in Kanter, 2013, stated: “When disability is considered through a cultural lens, ability is interrogated in much the same way

that gender is interrogated by feminist studies scholars and Whiteness is interrogated by the in studies scholars” (p. 12). Finally, the human rights model is a model that affirms the basic human rights of all people and was adopted internationally by the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2006. “No person with a disability, including a person with a cognitive or psychological disability, may be deprived of his or her legal capacity owing to a diagnosis or label of disability” (Kanter, 2007, as cited by Kanter, 2013, p. 13).

**Education for all Handicapped Students (1975)** was enacted to guarantee students with disabilities just access to public education and including one free meal each school day. Renamed the Individuals with Disabilities Education Act (IDEA) in 1990 (Individuals with Disabilities Education Act, of 1990, 2004)

**Inclusive education** is the practice of allowing students with disabilities to participate in educational situations with nondisabled students to the fullest extent possible to promote personal and educational growth (Ainscow et al., 2013).

**Individuals with Disabilities Education Act (2004)** is the most recent form of the Education for all Handicapped Students (1975), renamed the IDEA in 1990.

**Normalization** is an ideology of human services based on the proposition that the quality of life increases as one’s access to culturally typical activities and settings increases. Applied to individuals with ID/DD, normalization fosters deinstitutionalization and the development of community-based living arrangements and inclusion in community activities. (Landesman & Butterfield, 1987).

**Think College** is a national organization dedicated to developing, expanding, and improving inclusive higher education opportunities of people with intellectual disability Think College is housed in the Institute for Community Inclusion at the University of Massachusetts, Boston (Think College, 2020a).

**Transition** is the term that refers to a series of mandated steps in the K–12 special education system that requires schools to prepare a plan for students upon their exit from high school (Individuals with Disabilities Education Act, 2004). In 1978, the Division on Career Development and Transition (DCDT) was established to address concerns about the limited postsecondary outcomes of youth with disabilities (Field et al., 1998). In 2012, the National Secondary Transition Technical Assistance Center, now the National Technical Assistance Center on Transition (NTACT) was founded by the U.S. Department of Education to examine this topic. As a result, secondary transition laws were changed, and postsecondary education became a mandated option (Field, 1996).

### **Chapter Summary**

In this chapter I introduced the topic of inclusive postsecondary education within a historical framework of disability studies, equity and access in higher education, the field of developmental education, and the novel field of inclusive postsecondary education for students with intellectual and developmental disabilities. I also introduced the critical nature of the movement as well as the critical role of those implementing and administering programs. Finally, I framed the topic within a human rights standpoint clarifying that the denial of inclusive and equitable postsecondary education for students with intellectual and developmental disabilities might be considered the extension of

oppressive and dehumanizing treatment of individuals with intellectual and developmental disabilities which places the topic in a critical area of study for higher education.

## **II. REVIEW OF THE LITERATURE**

### **Introduction to the Review of Literature**

I included literature in this chapter to provide a deep contextualization for this novel PSE movement. Such deep contextualization is not extraneous because education takes place within social, cultural, and historical contexts (Freire, 1970/2013) and understanding the many aspects of the prior exclusion of individuals with ID/DD from society and how they must be addressed to facilitate changes is necessary for undertaking a critical approach. The review begins with literature on the history of program development, followed by literature documenting the benefits of inclusive PSE for students with ID/DD. Included next is the scant literature on program administrators and their role which is followed by literature on the beliefs and knowledge of K–12 special education administrators is reviewed. Literature at the K–12 level is included to inform the study because this type of research does not yet exist at the postsecondary level. Finally, literature that defines ID/DD and helps to expose some of the difficulties that occur in trying to define ID/DD and to include ID/DD in diversity and multicultural initiatives is discussed. The chapter concludes with an explanation of my conceptual framework.

### **Inclusive PSE Program History**

The history of Inclusive PSE for students with ID/DD has a distinctive trajectory that began with initial impetus provided by concerned stakeholders (i.e. parents and educators) working in localized settings (i.e. school districts and local providers such as vocational rehabilitation) with local resources. Their early work propelled the movement forward, eventually stimulating policy development, federal funding, and research. The

movement continues to gain traction demonstrating a nearly 70% increase in inclusive PSE program development over the past six years (Oakes et al., 2018). In the fall of 2019, there were 279 programs reported at institutions of higher education (Think College, 2019) serving nearly 4,000 students (Think College, 2020b).

Until recently, due to the independent nature of each program's development in localized circumstances, much of the research has been descriptive and practitioner based. In their 2008 survey of 52 PSE program coordinators, Papay and Bambara (2011) found great disparities across programs including different amounts of inclusion and different program outcomes (i.e. to gain employment, be with same-age peers, develop independent living skills, or participate in college classes). Papay and Bambara also found that 87% of program funding came from local school districts, illustrating a lack of federal, state, or higher education funding for program establishment. Additionally, 56% of surveyed programs were operated by local schools and not by the hosting colleges or provider services such as vocational rehabilitation. The data Papay and Bambara gathered in 2008 demonstrated great disparity in the levels of inclusion students experienced on the college campuses which suggests that source of funding may impact inclusion as funding was predominantly from K–12 schools and appeared to be tied to program administration. With a 64% response rate and a higher rate of responses from 2-year institutions (58%) compared to and 4-year (42%) institutions, Papay and Bambara's study may have been subjected to bias in response from participants self-selection into the study, and their results may not accurately reflect program funding and development at 4-year schools because of the lower 4-year response rate.

Taking a broader sweep of program development across time, two literature reviews cover the literature available during two time periods. The first covered all the literature available from the mid-1970s to 2001, and the second covered the period 2001-2010. These two reviews provided an overview of major developments across large time periods illustrating the shifts in program content and development as well as shifts in research capacity over time. These literature reviews also provided a better way to gauge the growth trajectory of the movement in a way that looking appraising smaller, individual, localized, and descriptive studies do not and helps to historically contextualize the present state of the development of inclusive PSEs.

In their 2001 literature review, Neubert et al. reviewed 27 published articles and found that the data spanning 3 decades consisted primarily of program description and policy briefs. In contrast, Thoma et al. (2011) examined an additional 24 pieces published between 2001 and 2010 and found that, although the majority continued to be descriptive, a distinctive language had begun to develop with which to describe program features. Language specifically focusing on program designed, clearer articulation of program goals, and greater attention to guiding philosophies were present in the studies between 2001–2010. “Inclusion” was one of the philosophies noted to develop over time, and increasingly, studies became more focused on noting the amount of time students spent with peers in both inclusive courses and other campus activities rather than in pull-out programs. Thoma (2013) also noted that research during this time frame was frequently designed to help build knowledge in the field so that individuals starting programs in separate locations could translate such descriptive research into practices for their immediate use in their local context. Research during this time also expanded to include



the impact of parents and transition services on student attainment of higher education goals. Parent roles proved to be of a particular advocacy nature while reaching out to transition services helps to establish a K–12 pipeline to higher education.

### **Parent Advocacy**

Parents are major stakeholders in the inclusive PSE movement and are credited with much of the work done in the early days of program development. The literature on parent perspectives demonstrates the importance of their role and how their intentional advocacy helps their children navigate post high school opportunities. In 2016, Leuchovius and Roy conducted qualitative interviews with five parents of youth with ID/DD and found that the parents they interviewed exhibited a robust advocacy in their actions. Leuchovius and Roy noted that parents (a) established urgency, (b) formed powerful coalitions, (c) created a vision for change, (d) communicated their vision, (e) removed obstacles, (f) created short-term wins, (g) built on the change, and, (h) anchored changes in culture. Leuchovius and Roy referred to parents as “parent leaders.” While not a large study, it is notable that all the parents surveyed indicated their role went beyond that of a typical parent in a school setting and involved advocating for changes in education and cultural norms.

In their 2016 qualitative study, Rossetti et al. interviewed parents of eight students with ID/DD who were selected from a larger student sample based on the students having reported that their PSE experiences were very meaningful. Data were collected across multiple, semi-structured interviews and analyzed using an interpretivist paradigm with the intent of understanding parent experiences. Rossetti et al. found that parents in the study were very active in their child’s PSE experiences and described themselves as

fierce advocates and creative problem solvers. Parents also influenced their children by setting high expectations, focusing on their child's interests, and encouraging their child to try new things. Regarding advocacy, parents reported that they felt responsible for their child's success, they persisted in the face of rejection, and many (7 out of 8) were employed in or had experience in the disability field which helped them develop knowledge and skills specific to their situation parenting a child with a disability. The findings in this study align Leuchovius and Roy's findings in regard to the parent-advocacy role; however, both studies are admittedly small, and may represent a propensity for self-selection by more actively involved parents rather than a sample representational of all parents of students with ID/DD in PSEs.

In 2018, parents were credited with starting a partnership with professionals in central Pennsylvania with the mission of creating inclusive postsecondary programs, for students with intellectual disabilities leading to competitive employment. This parent-driven partnership includes a 12-member board of directors, advisory committee, executive committee, business partnership committee, full time executive director and part time executive assistant, and a consultant to provide technical assistance. Since its inception, the partnership has funded 7 new programs and helped 2 existing programs expand (Partin & Landis, 2018). While these studies indicate a strong advocacy among parents, as the movement grows, further studies are needed on the thoughts and actions of a wider range of parents whose children attend PSEs. The current range of studies are small may reflect parents who self-selected to participate or who were selected because of their work.

## **Benefits of Inclusive PSE**

Research on the benefits of student participation in CTPs has been conducted in an array of areas including employment outcomes, increased social circles, increased independent living skills, and increased academic skills. In 2008, Flannery et al. examined the employment outcomes and predictors for success of 123 transition-aged students and adults eligible for vocational rehabilitation, who, as part of their services, attended a college-based, short-term training program. The program included financial support, receiving workforce and career planning services, and the opportunity to take additional course work including developmental math, reading, and writing, as well as the provision of direct job support once employment was attained. Flannery et al. found that the students who completed the PSE training had statistically significant higher wages and worked more hours than students who dropped out of the program. In their study, Flannery et al. found no difference in these numbers when controlling for sex, age, or ethnicity, demonstrating that the single factor responsible for better employment outcomes was remaining in the PSE training. Employment rates for students remaining in the training were high (85.8%) and of the training provided, the three primary variables supporting student success were (a) access to financial assistance, (b) career planning, and (c) vocational coursework. Limitations to the study were its local geographic context and sampling from only one program as well as a lack of random sampling, which is typical of within-program analysis.

In a more expansive research study, Migliore et al. (2009) analyzed student outcomes by accessing a vocational rehabilitation data base containing 36,154 individuals receiving vocational rehabilitation services, of which, 1,223 had participated in PSE as

part of their vocational rehabilitation. Migliore et al. found that individuals with ID/DD who attended PSE and achieved a higher level of education also achieved higher rates of competitive employment than did those who attended other types of rehabilitation training. In their study, 58% of individuals attending PSE gained competitive employment with an average weekly compensation of \$338. In comparison, 48% of those attending other types of rehabilitation training gained competitive employment with an average compensation of \$316/week. Students who received no training through either PSE or rehabilitation services had only a 32% rate of employment with a considerably lower income average of \$195/week. Studies such as this one have the potential to highlight the benefits of inclusive PSE on a larger scale with the ability to compare the impact of inclusive PSE to the impact of other types of services. Research such as this supports the movement towards provider and disability services using funds to support students with ID/DD at PSEs, a trend that is helping improve access (Hart & Weir, 2013).

McConnell et al. (2012) constructed a list of beneficial non-academic student behaviors developed from PSE opportunities through a secondary analysis of qualitative and quantitative secondary transition literature which included both employment training and education programs. From the 35 studies that met their inclusion criteria, McConnell et al. constructed the following list of ten non-academic student behaviors that support successful post-school outcomes (i.e. employment). Their list includes (a) having knowledge of personal strengths and limitations, (b) knowing how to take action regarding strengths and limitations, (c) general disability awareness, (d) employment, (e) goal setting and attainment, (f) persistence, (g) proactive involvement, (h) self-advocacy, and (i) ability to utilize resources. McConnell et al.'s methodology allowed for the

development of a comprehensive list of valuable skills students can develop in order to gain successful employment. These constructs are valuable because they can be used for both instruction and assessment purposes. The study demonstrates the value of compilation and cross-case analysis.

In 2013, Ross, et al. reported on the post-program completion outcomes of 125 students with ID/DD who graduated from Taft College's Transition to Independent Living program. Taft is an example of a PSE program and provides students with enriching college experiences, an interactive and inclusive college environment, and career and educational opportunities at the postsecondary level. In this study, data from 2011 indicated that 84% of the students who attended the program were employed for pay with 86% receiving at or above minimum wage. Their study also indicated that 94% of the graduates from the Taft program lived alone or with a spouse/roommate in an independently owned or rented apartment or house demonstrating the successful development of their independent living skills. Eighty-eight percent of the Taft graduates managed their own finances. Many of the graduates owned a car, although Ross et al. did not state whether they were licensed drivers, which would indicate a skill level not generally associated with many individuals with ID/DD. This information was presented as a report and was therefore descriptive of one unique PSE program, which, as noted above, is common. However, their information supports the overall findings from multiple studies that PSE opportunities increase the employability and employment opportunities for individuals with ID/DD.

Fabian (2007) found the same employment benefits apply for minority students with ID/DD who attend PSEs. Fabian analyzed data from 4,571 students from a transition

program of whom 61% were African American, 24% Latino, and 57% were from low income communities. Data indicated that those who participated in a transition program gained employment at the rate of 68%, considerably higher than the national rate for minority students with ID/DD (42%). In a 2015 study, Moore and Schelling measured the employment outcomes of students with ID/DD two years after leaving high school, comparing employment outcomes between students who attended a 2-year PSE and those who did not. Students enrolled in PSE programs reported 100% employment, whereas those who did not attend programs reported 53.5%. The rate for those who attended PSE programs dropped to 91% over the next 2 years versus the same 53.5% for those not attending. The second measurement measured true employment results, not campus- or program-related employment. Although the study was small ( $n = 34$  PSE respondents), it did compare groups of students attending two different types of PSE programs (one more inclusive than the other) with a control group of students from the 2009 National Longitudinal Transition Study who received no PSE.

More recently, Qian, et al. (2018) explored predictors associated with paid employment outcomes for 228 college students and found that different aspects of the PSE experience contributed to different amounts and type of employment success. Among the variables that they examined, taking inclusive courses exclusively was the best predictor for obtaining above-minimum wage employment. Their research indicated that students who took only inclusive courses were 4.65 times more likely to earn above a minimum wage in comparison with students who took non-inclusive and more specialized courses. Other factors contributing to better employment outcomes included prior work experience, volunteering, community service, and attending on-campus

events. Although a small study, this study was one of the first to clearly link the benefits of full inclusion with positive employment outcomes.

A bulk of the research on employment is provided in the form of reports, including the most recent Executive Summary of the Year Four Annual Report of the TPSID Model Demonstration Projects (2018-2020) (Grigal et al., 2020). Regarding student employment, in this report, Grigal et al. reported that 93% of students in model programs participated in at least one employment or career development activity, and that 53% (n=519) held at least one paid employment position with 35% (n=345) hold positions that ear at or above minimum wage while enrolled in the program. Employment data for students one year after exiting their program was 64%, which is significantly higher than the national employment rate for adults with ID/DD which is currently 18% (National Core Indicators, 2019). While employment during their time in programs is generally reflective of program requirements, the benefit of these reports is that they can link program experiences to post-program outcomes.

Besides receiving a paycheck, other benefits associated with employment include other types of compensation such as paid vacation, time off, and access to health insurance, additional skill building activities, having a sense of purpose, and building social networks. Benefits of social networks come through the additional time spent with co-workers at work which help facilitate deeper relationships, common experiences, and a shared vocabulary and culture. These relationships also generate a greater pool of friends with whom to enjoy leisure activities. Work relationships help generate a greater pool of friends with whom to enjoy leisure activities. Forrester-Jones et al. (2004) mapped the social networks of 213 individuals with ID/DD living in the community as

part of a 12-year follow up study and found that those relegated to small community group situations tend to have smaller social networks, while Prohn (2014) used a mixed-method assessment of seven students in an inclusive PSE and found that social inclusion is a function of belonging. The students in Prohn's study stated that PSE provided the opportunity to meet new social contacts, contribute to their community, and helped them find ways to stay connected even when physically separated from their social group (i.e. using social media). Indeed, college "had the potential to function as a social incubator" (p. 201). To collect data, Prohn trained 23 college students with ID/DD in gathering pictures and in story telling techniques with which they gathered their own data and their input contributed greatly to the development of the study, however, one limitation of the study was that students had to get release forms from the subjects in the photos and many did not do so for a variety of reasons rendering some data unusable. The strength of this study was in the purposive inclusion of student voice, training of the students in research techniques, subsequent qualitative and quantitative analysis, and presentation of the data.

In a descriptive report of a model TPSID program, Folk, et al (2012) reported that students with ID/DD in PSE show improvement in reading and writing skills and course completion while Hinzman et al. (2017) reported that students with ID/DD who were taught a three-step paraphrasing strategy outperformed the control group considerably. The study included ten participants with ID/DD enrolled in PSE who were randomly assigned to either the intervention group or a control group. After being provided twelve 60-minute lessons over a six-week period, the students receiving the paraphrasing instruction outperformed the control group in the number of main ideas recalled and the



number of details recalled. A limitation of this study was that the students were not tested at a further date to determine if the effects of the intervention lasted over time.

Landes (2017) found that increased education was associated with lower mortality risk for adults with ID/DD, although the association was not as strong as it is for adults without disabilities, and their study was not able to determine which aspects of increased education contributed to better health. Landes also pointed out that educational attainment can translate into other tangible benefits such as understanding health issues and being able to seek help and address health issues properly, as well as achieving employment with better benefits such as health insurance and increased social resources.

Measuring academic and employment benefits is one way to determine how university policies and procedures impact this student population. However, other factors as well can contribute beneficially to student success and retention. Some of these beneficial factors, such as a sense of belonging and the establishment of social networks, have long been recognized, whereas others are benefits that non-disabled students and faculty receive as they forge relationships and experiences with students with ID/DD on campus and in the classroom (Harrison et al., 2019).

Building social networks and experiencing a sense of belonging are prime contributors to academic success and persistence for non-disabled students (Tinto, 1987). The same is true for students with ID/DD. In their study of eight first-year students with invisible disabilities (disability not readily apparent), Vaccaro et al. (2015) found that the development of self-advocacy skills, mastery of the student's role, and establishing social relationships were the prime contributors to students' development of a sense of

belonging on campus. One primary way to establish social networks is the use of student mentors (Jones & Goble, 2012; Kleinert et al., 2012).

Postsecondary opportunities for students with ID/DD also support an increase of their self-determination skills. In a study using focus groups of college students with ID/DD, Getzel and Thoma (2008) used focus groups to ask 34 students ranging in age from 18–48 years questions about developing self-advocacy skills at college, and what skills they felt were important for college students to develop to become self-advocates. According to the students in the study, the following activities contributed to developing their self-advocacy and self-determination skills; developing problem solving skills, increasing self-awareness, setting goals, managing self, learning how to seek services on campus, form relationships with professors and instructors, and developing support systems on campuses. Other studies examining self-determination at the college level include individual case studies such as Hanson et al. (2018) who followed one student in a college transition program and noted the value of fading supports over time to support the student's development of self-determination skills.

In addition to the benefits that students with ID/DD gain from supports, in some circumstances, such as mentor support, the students providing the supports are also receiving benefits demonstrating that mentorships are one type of relationship that have a reciprocal value. Griffin et al. (2016) reported that volunteers who are trained to facilitate campus integration of students with ID/DD reported that they also experience personal growth, increased understanding of disability and supports. They also developed a desire to continue such supportive work as a career choice or to shift the focus of their current career choice to include the needs of individuals with intellectual disability (Griffin et al.,

2016). Carter (2019) gathered data using an online survey from 250 college student mentors at five universities with inclusive PSE programs and noted that the top motivations for mentoring are; alignment with personal values (94%), expecting the experience would be fun (91%), a desire to give back to the community (88%), an interest in learning more about disability (77%), personal ties to people with disabilities (69%), alignment with religious values (55%), and alignment with future career plans (54%). In addition to gathering information on student motivation for volunteering in the first place, Carter also collected data on the benefits that student mentors reported. Benefits included that mentors (a) got new friendships (99%), (b) developed a greater appreciation for diversity (97%), (c) became more comfortable interacting with people with disabilities (97%), had fun (97%), became better advocates (97%), and became better informed about the issues and barriers facing individuals with ID/DD (99%). The experience was least likely to impact students' stress levels, grades, or study skills. Other studies have also shown that peer mentors, faculty, students, and others in the community who interact with students with intellectual disability report a reduction in negative biases, in discriminatory behaviors, and in erroneous beliefs about individuals with ID/DD (Carter et al., 2001; Findler & Vardi, 2009; May, 2012).

Research on the benefits of inclusive PSE for individuals with ID/DD, like research on college student growth in general, reaches across many domains (e.g., academic, social, personal development) and takes many forms. In this particular area, however, the wide variety of program styles and curriculum development organized in isolated situations makes it difficult to generalize studies across all students in every situation. Additionally, given the small size of this student population who are also

considered vulnerable, it is important to consider participant fatigue when conducting research.

Most of the empirical research on students with ID/DD focuses on student benefits and outcomes, with a small portion exploring student supports (Griffin et al., 2016), program implementation, and integration of programs on college campuses (Kavulik, 2017; Stolar-Martz, 2016).

### **Administrators of Inclusive PSE Programs**

The role of the administrator of PSE for students with ID/DD is novel. In 2014, volunteers were still doing much of the work to organize PSE efforts, with minimal funding (Parent-Johnson, et al., 2014). Those with at least two years of experience are considered experts because so few individuals have served in these trailblazing positions (Grigal, Hart, & Weir, 2011). There is much anecdotal and descriptive information about the work that is performed and the obstacles that are overcome, but there are no specific criteria for designating individuals as having trained for administrative positions or for what such training might look like. Grigal et al. (2011) also noted the need to create standards to guide best practices, and the literature on PSE programs for students with ID/DD lacks reports on the experiences of schools, agencies, and individuals who have created such opportunities where none existed before. Sharing these experiences of program development can help others start similar programs (Grigal, Hart, & Lewis, 2011; Neubert et al., 2001).

In 2015, Plotner and Marshall stated that “directors of new PSE programs have few research-based guidelines to provide direction for integrating programs within colleges or universities” (p. 58). However, two recent publications (Baker et al., 2018;

Francis et al., 2018) focused on compiling lists of administrator duties with suggested outlines for program implementation. Baker et al. (2018) provided a framework for developing inclusive PSE programs for students with ID/DD. Their framework included examining prior literature and videos on program development, exploring the philosophical foundations of inclusive PSE, and also included following a prescribed series of implementation steps which included becoming familiar with one's institutional mission and local community needs, setting up an advisory board and meeting with various campus constituents, and establishing funding, program space, followed by creating application materials, recruiting students and planning for program evaluation. Francis et al. (2018) also provided a list which includes forming a program development committee, learning from other PSEs, gathering community feedback, petitioning university leaders, and hiring program staff. Papay, et al. (2019) also provide administrators with guidelines for program evaluation.

Administrators of novel PSE programs occupy unique roles on college campuses. Within their programs, administrators create program guidelines, establish outcomes, and develop curricula to support the development of their students' academic, vocational, and social skills and honor students' individualized goals (Miller, et al., 2018; Papay, et al, 2019). In addition, they establish cross-campus collaborations and coalition building to ensure full campus access and inclusion for the students in their program who may or may not be considered matriculated (Hines et al., 2016; Smith & Benito, 2013). Part of this collaboration building involves establishing new connections; educating other administrators, staff, and faculty; and navigating resistance (Paiewonsky et al., 2013).

In addition to building campus relationships, administrators also develop relationships with federal, state, and locally funded service providers, including vocational rehabilitation and other community organizations that normally provide services for adults with ID/DD. Administrators also establish business partnerships in the community that can enlarge the range of services and experiences offered to students, such as internships and work opportunities.

Information sharing is a key to advancing the PSE movement (Miller et al., 2018). Repeated explanations of the programs are needed continually to educate new staff regarding program models and outcomes (Paiewonsky et al., 2013). In many respects, administrators' responsibilities are similar to those of special education teachers and directors in K–12 schools. Unique special education duties, according to Dinero (2014), include “cultivating a cultural understanding of disability both individually and systemically” (p. 7).

In 2019, Bumble et al. conducted a study to explore how campus and community stakeholders conceptualize inclusive higher education for students with ID/DD. They assembled teams at three campuses with 172 participants who generated over 454 unique ideas to contribute to the conversation. Ideas were grouped in 12 categories, which included supports (e.g., peer-mediated supports and residential supports), program components (e.g., principles and design), experiences (e.g., residential life, work experiences, and friendships), partnerships (e.g., school districts and families), skills (e.g., independent-living and self-determination), training (e.g. of campus faculty and staff, of program staff), attitudes (e.g., of campus faculty and staff, of other students), the campus community (e.g., campus safety and career services), the surrounding community

(e.g., transportation and faith communities), disability providers and organizations (e.g., vocational rehabilitation and disability-focused organizations), school systems (e.g., middle and high schools and dual enrollment), and families. This list is long and large, and it is therefore not surprising that Vaughn (2019) found that best practice guidelines for administrator roles must include communication, involvement, and training. In 2017, Kavulic conducted a case study at his own institution to explore how program stakeholders, namely program staff and faculty, contributed to the institutionalization of their inclusive PSE program. Kavulic found that personal stories and advocacy constitute a prime way for administrators to gain buy-in for their programs, and that their work can be considered as change agents and system disruptors, but to date, no studies have sought to gain a better understanding of how administrators' prior personal, professional, and educational experiences and beliefs about students with ID/DD help prepare them for their roles, and no studies have taken a critical approach to the topic.

There is little empirical research on administrators of PSE programs for students with ID/DD or in other educational support areas such as offices of disability services (ODS) and DE. With respect to ODS, Breslow (2016) has noted that the voices of disability service providers are absent from the literature on disability services, although research in this area does include students' and instructors' voices. Theoretically based administrator studies are also lacking for DE, which nonetheless boasts a rich oral history of practitioners that highlights beliefs in educational equity as well as personal qualities such as caring for students (O'Donnell-Lussier & Shetron, 2018; Rose, 1988).

The field of DE does provide advice for conducting studies of smaller educational communities within larger educational contexts. In 2012, Stahl pointed out that service

providers, faculty, staff, and administration should all be included when conducting research on effective practices (Armstrong, 2012) and Stahl et al. In 2018, Stahl et al. underscored the value of qualitative research in educational fields that focus on “multiple, unique populations that demand contextual details to be at the forefront of questions being asked and research being conducted” (p. 2). The current literature on inclusive PSE for ID/DD echoes this practice of including input from multiple stakeholders (Francis et al., 2018). As part of this research focusing on unique populations in highly contextualized settings, understanding the experiences and beliefs of administrators who forge inclusive paths for PSE students with ID/DD may also help determine effective practices and inform other leaders and practitioners in DE or ODS. Knowledge sharing at the practitioner level is crucial for supporting administrators and other practitioners working in such programs (Hines et al., 2016).

Suggestions for administrators are mentioned by others whose work is tangentially related. Jones et al. (2016) examined the perceptions of faculty members at a 4-year university with an inclusive PSE program. Their findings indicated that faculty felt that more communication with program coordinators was needed. Faculty wanted more advanced notice and information about the inclusion required as well as about student characteristics. Although faculty felt that the inclusion of students with ID/DD in their courses was beneficial, stretching their teaching methodologies and provoking much self-reflection in course delivery, they also feared the unknown and wished that program coordinators would send a brief email or short video to help prepare them and alleviate their fears.



An exploratory study of 87 directors of community-based developmental disability provider agencies stated that a lack of awareness and knowledge of PSE programs prevented them from suggesting PSE as options for the individuals with ID/DD whom they served (Sheppard-Jones et al., 2015). These directors indicated that the lack of knowledge was even greater for the parents of students with ID/DD. Sheppard-Jones et al. (2015) pointed to administrators in higher education as an integral component in providing welcoming environments for all students and participating in dialog between agencies to increase awareness and support students in developing a college plan. To be effective, educators must have an understanding of the students they serve.

### **Administrators of K–12 Special Education**

Although little empirical research exists on inclusive PSE administrators' personal, professional, and educational experiences and their beliefs, research on the experiences and beliefs of K–12 special education administrators may inform the topic. There is, however, a primary difference between K–12 special education and inclusive PSE for students with ID/DD; K–12 education for students with ID/DD is federally mandated (IDEA, 1990, 2004) while PSE for students with ID/DD is not currently mandated. Instead, inclusive PSE is primarily stakeholder driven and individuals undertake this work because they think it is needed, not in response to mandates (Thoma, 2013). At the college level, however, programs have a different set of compliance issues that are federally mandated mostly pertaining to disability accommodations and anti-discrimination laws (ADA, 1990).

In response to federal special education mandates, the role of K–12 administrators expands to include new duties such as designing, leading, and managing inclusive

programs along with managing and training special education personnel and completing additional paperwork (Ball & Green, 2014; Sage & Burrello, 1994). Not only are administrators required to learn and manage additional tasks relating to special education management, Davies (2018) stated that ill-prepared principals may violate the rights of students with disabilities. In exploring the role that training and exposure to special education and students with disabilities has on administrator performance, Templeton (2017) conducted a two-phase, sequential mixed-methods, multiple case study with 61 principles participating in phase one of the study. Phase one measured the special education knowledge and skills of the 61 principles and results of this data collection provided a scale of skills from which to select four principles based upon their self-report as either highly skilled or typically skilled. Principles' self-reports were validated by teachers in their district through a teacher survey measuring the same skillsets principles self-reported on. Results showed that principals' effectiveness in their special education administrative roles varied according to their level of prior special education knowledge and that those with knowledge of special education beyond compliance and legal aspects were more likely to move beyond compliance to understanding and supporting specialized instruction and providing key opportunities for students with disabilities to get additional support and opportunities to develop. Templeton's research indicates that administrators who are exposed to a broader array of special education issues and real-world scenarios are better prepared to address the more pervasive needs of students with disabilities and support their teachers to do the same.

Praisner (2003), who developed the Principals and Inclusion Survey, associated K–12 principals' positive experiences with students in special education and exposure to

special education concepts with more positive attitudes towards inclusion. In 2010, Vasquez used an adaptation of Praisner's Principles and Inclusion Survey with 175 special education administrators and results of the study indicated that principals who had prior positive experiences with students with disabilities were more likely to place them in more inclusive educational settings. Allan (2016), also conducted a study of 34 administrators using an adapted format of Praisner's survey with findings indicating that, although most administrators stated that they favor inclusive education, those with more specialized training in special education and related services were more likely to make inclusive placements for their students. Taking Praisner's work a step further, Jacobs-Bell (2014) examined the attitudes of 65 principles and school administrators using a theory of behavior change. In his study, Jacobs-Bell's made a direct connection between administrator or principal personnel characteristics, training, and experiences and their increasingly positive attitudes towards inclusion. These and similar studies provide a precedence for undertaking a study exploring the connection between experiences and beliefs in administrators of inclusive education at the postsecondary level considering the additional element, as stated above, of being non-mandated and includes creating equitable educational spaces where none currently exist.

### **Understanding Intellectual and Developmental Disability**

This section of the literature review does not focus on the broader categories of diversity and multiculturalism in education, but instead, serves as a primer to those not acquainted with ID/DD and helps to illuminate various aspects of diagnosing, naming and labelling ID/DD which make it difficult to describe or quantify for educational or

social purposes. Building this understanding of this unique college student population is important for contextualizing the study.

Understanding new student populations is key to serving their educational and social support needs (Higbee, et al., 2005) and the literature on diversity and cultural awareness in education is vast. This literature includes studies on specific populations (e.g., veterans, women, minorities, and others) and attributes (i.e., cultural, political, economic, racial, gender, and sexual orientation). Very seldom is disability considered when discussing student diversity (Davis, 2011; King, 2009). The term “abilities” is sometimes used when discussing students with disabilities, however the use of this catchall phrase creates a situation in which a wide variety of abilities and disabilities are blended into one encompassing term. This can inadvertently, mask the specific needs of the individuals the term seeks to include. Additionally, disability can coexist with all other types of identity and cuts across all socioeconomic levels.

The American Association on Intellectual and Developmental Disabilities (AAIDD, 2018) defines intellectual disability as “a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. The disability originates before the age of 18.” Schalock et al. (2007) noted that the definition cannot stand alone without further clarifications regarding specific limitations in functioning and support needs. Although frequently lumped together, autism spectrum disorder and intellectual disability are distinctly different diagnoses and stand in distinct contrast to other invisible types of ID/DD such as traumatic brain injury, depression, schizophrenia, and learning ID/DD

(e.g., dyslexia, AD/HD, dyscalculia, dysgraphia). Any of these other conditions can coexist with intellectual disability.

ID/DD can be the result of a congenital condition such as Down syndrome, but poverty, poor nutrition, lack of medical care, and culturally impoverished environments contribute to a higher rate of diagnosis, and, in the U.S., people of color and children from low socioeconomic backgrounds are diagnosed with ID/DD at higher rates, indicating that social inequities contribute to this diagnosis too (Morgan, et al., 2015; Ryan, 2012).

Individuals with intellectual disability make up 1–3% of the world’s population and approximately 6.5 million people in the U.S. have an intellectual disability (Special Olympics, 2019). In the U.S., the rate varies greatly, and there is no established method for measuring prevalence. Students with intellectual disability are the least likely of students with any type of disability to enroll in any type of PSE within four years of exiting high school (Newman et al., 2009). Increasing numbers of students with intellectual disability are pursuing higher education because of increasing opportunities and better P–12 education and transition services. Their numbers, however, are not matching the rates for the general public or other students with other types of disabilities. Regular student enrollment increased 38% between 1999 and 2009 and is expected to grow another 14% by 2020 (Snyder & Dillow, 2012). A similar increase is expected for students with other types of disabilities in accordance with prior enrollment trends, which showed that in 2005, 19% of students with disabilities participated in PSE compared with 40% of the general population (Wagner et al., 2005). These rates have increased to 39% for students with other types of disabilities and 60% for the general population, while the

rate of students with ID/DD attending PSE trails behind considerably with only 25% of students with ID/DD attending PSE of any type (Bouck, 2014; Sandford et al., 2011).

Label ambiguities exist for college students with intellectual disability (Quick et al., 2003). Terms such as developmental disability, intellectual disability, borderline intellectual functioning, mild intellectual disability, and learning disorder-not-otherwise-specified are often used interchangeably, although they are not actual diagnoses (Harrison & Holmes, 2013). Some programs use the term “intellectual disability,” others use “developmental disability,” and some use both. Although there is some overlap between the two, the distinction between them is that a developmental disability is a delay in any area of normal development that may or may not include intellectual disability. Both developmental and intellectual disability include medically determined conditions such as Down syndrome and cerebral palsy; however, the individual with physical disability and no cognitive deficits would not be categorized under the umbrella term intellectual disability. Additionally, a person with autism spectrum disorder may have social adaptive problems but no cognitive deficit. In England, the preferred term is learning ID/DD, which has an entirely different connotation in America, making information sharing across cultures difficult. In America, learning ID/DD generally refers to dyslexia, dyscalculia, dysgraphia, and other processing disorders, as well as ADHD and executive functioning/organizational disorders. The literature shows multiple perspectives on terminology. ID alone, however, is less inclusive than ID/DD, although to use ID alone in the present study would align with Think College and the HEOA.

The use of specific definitions and terminology can impact the individual in more than one way. Terms and definitions can lead to the stigmatization of an individual, to

stereotyping, and to the perpetuation of social inequities (Ditchman, et al., 2013). Obsolete, stigmatizing terminology includes idiocy, feeble-mindedness, mental deficiency, mental disability, mental handicap, and mental sub-normality (Schalock et al., 2007; Loewen, & Pollard, 2010). The term intellectual disability has gradually replaced mental retardation over the past 20 years. Although clinically correct, mental retardation has negative, devaluing connotations (Finlay & Lyons, 2005; Snell & Voorhees, 2006), as does the endless supply of other derogatory terms such as *slow*, *dull*, *mentally defective*, *subnormal*, *moron*, and *imbecile* (Schalock et al., 2007). In 2010, in a step toward unifying terminology, President Obama's Rosa's Law formally replaced mental retardation with intellectual disability at the federal level in all federal acts pertaining to disability. (Rosa's Law, 2010) My use of the terms intellectual disability coupled with developmental disability (ID/DD) throughout this study was intended to be more inclusive. Other studies used ID alone, ID/D, or ID/DD, frequently referring to the same population. Grigal, Hart, & Weir (2013) noted that "confusion in terminology is evidence of the current lack of established practices and guidelines for PSE for student with ID" (p. 53).

There is a tendency to overgeneralize the concept of disability and to disregard the unique nature and support needs of individuals who experience and cope with ID/DD. Imprecise language and a lack of understanding of the impact of ID/DD on the lives of those who live with ID/DD can lead to policy or program implementation that may not accomplish desired results because of choices in language and terminology. Imprecise or misinterpreted definitions can lead to programs and policies that may serve one portion of a population but exclude another. Understanding these distinctions is crucial for

understanding this study's topic and context. Failing to understand these distinctions can lead to subtle forms of oppression. For instance, if an individual becomes intellectually disabled through head trauma at an age past 18 years, will the program include them if their program is designated for students with intellectual disability defined as occurring before the age of 18 and for students who were eligible for special education services in K–12 education.

Although specific terms may designate students with ID/DD, caution should be exercised when applying overarching characteristics to an entire group of individuals. Beyond diagnosis criteria, students with ID/DD have, like all other people, individual strengths and weaknesses. However, by learning about some of the pervasive characteristics of students with ID/DD, it becomes easier to see how interactions with students with ID/DD might require a bit more patience, support, and advocacy (Getzel, 2008). These characteristics can include slower or delayed academic progress and intellectual development and a lack of self-advocacy and self-determination skills (Field et al., 2003; Grigal et al., 2003). Such students may have slower processing skills (Kail, 2000), which can be exacerbated by the fast pace of contemporary society (Yalon-Chamovitz, 2009). They may also have difficulty acquiring social and independent living skills.

Intrapersonal and interpersonal skills may also be slower to develop, and students may lack self-knowledge related to their disability and how that disability affects their learning and understanding. Such self-knowledge can increase the individual's ability to determine support needs and to seek and obtain appropriate support services, as well as



the ability to persevere when obstacles are present (de Fur et al., 1996; Getzel et al., 2000; Getzel et al., 2004).

Students with ID/DD may have trouble in interpreting social situations. This difficulty, combined with a lack of self-advocacy skills, can leave them more open to being taken advantage of than individuals with other types of ID/DD. Individuals with ID/DD are more likely to be victims of teasing, persuasion, money problems/theft, and other forms of abuse (Fisher et al., 2016; Fisher et al., 2013). Students with ID/DD require age-appropriate information conveyed in simplified ways and in simplified environments (Yalon-Chamovitz, 2009), using plain language, clear rules, and protocols (Karreman, et al., 2007).

Although the above list indicates some of the more obvious differences between individuals with ID/DD and individuals without ID/DD, it does not consider the value of addressing individual differences and strengths which are present in all humans, or the importance of supporting the development of and affirming individual personal identities (Elks, et al., 2019). Building on this idea of affirming individual strengths and identity, Jones, et al. 2015 noted that “difference is not synonymous with incompetence” (p. 2) and that full inclusion provides identical opportunities to students with and without disabilities, not separate or segregated experiences.

### **Strengths based approach**

According to Noddings (2015), “we should recognize education as a multi-purpose enterprise that can be unified under one great aim: to produce better adults” (p. 232) and we should not feel that it is elitist to recognize differences in ability. As educators, we should rise to the task of finding out what each person can do. Myers et al.

(2015) have pointed out that the strengths and abilities of students with ID/DD may be more difficult to recognize and cultivate because they may be obscured by or intertwined with student weaknesses. To be effective, instructors and staff must be sensitized to look beyond weaknesses to find strengths, and they must be able to adapt to a wide range of abilities and behaviors. Nelson and Guerra (2014) found that of 111 teachers and educators whom they surveyed, the majority considered the source of classroom problems to be the result of a student deficit rather than a cultural or social difference. This revealed that teachers and educators lacked training in cultural awareness and an understanding of other sources of difficulties besides student deficits. Nelson and Guerra categorize deficit thinking under the term “beliefs” and make the case that “beliefs” can be shifted through obtaining cultural knowledge regarding students. They describe identity, culture, language, and relationships, as “the heart of culturally responsive teaching, learning, and leading” (p. 67), but, as noted above in the descriptions of ID/DD all of these attributes can be present in many different ways and in different combinations for each individual student with ID/DD. Therefore, applying strengths-based educational methods to students with ID/DD becomes a highly individualistic endeavor.

Many educators are familiar with types of accommodations required by students who have physical disabilities, such as assistive technology, guide dogs, closed captioning, deaf interpretation, extended exam times, or oral administration of exams. When a student has an invisible disability, however, it becomes more difficult to understand the student’s specific support needs, and in many cases, unless a disability is disclosed, college personnel are unaware that a disability or support need is even present.

## **Freire: Critical Conceptual Framework**

Freire saw such dawning moments as markers of progress that represent a potential for a new reality—precise moments when a critical stance should be taken and can be most beneficial. In this study, I used Freire’s critical educational philosophy both as a conceptual framework and as a rubric for analysis. Freire’s ideas lend a needed critical lens and language that reach beyond personal stories (Kavulic, 2017) to present a platform for human rights. His term oppression leaves no doubt that dehumanization is not a chosen position but is a circumstance imposed by an oppressor. A primary purpose of this study is to raise a critical awareness about this new student population and their educational needs within the DE community, to stretch ideas of what inclusive PSE can be, and to expand student support knowledge in the DE community.

Freire originally developed his educational philosophies in Brazil and Latin America in the 1960s and 1970s. Within his local setting, he viewed illiteracy as a tactic used by the government to subjugate poor citizens, creating a state comprised of oppressors and oppressed within systems set in place to maintain that status quo. Freire maintained that both the oppressors and the oppressed contribute to the condition of oppression. In response to local conditions, Freire developed a literacy program to help oppressed peasants become aware of their local realities, including imbalanced structural systems that maintained the status quo keeping them in poverty. One of his goals was to help them develop a vision of their situation from their own perspective in order to create change and to gain control in directing their own futures. His literacy initiatives became so successful in prompting civic engagement among the poor, which in turn supported

their participation in revolution, that he was imprisoned by the Brazilian military's coup d'état as an enemy of the state in 1964 (Freire, 1970/2013).

Freire's method for developing his successful literacy program with the poor of Brazil and Latin America relies on a critique of traditional pedagogy. To Freire, the educator, in solidarity with his or her students, must question local realities and create an individual, localized understanding of their place within the context of larger systems such as governmental regimes and an understanding of their historical, cultural, and social settings (Harro, 2013; Tatum, 2013). The educator assists the student in constructing the student's own understanding of the student's world, beginning by pointing to local realities and asking, "what do you think about that?" (Freire et al., 2014, p. 18). This constructivist educational method, or problem-posing education, is supported by the educator's guidance and knowledge, but it also requires the educator's humility and willingness to recognize students' constructed realities and to suspend judgement regarding them.

Originally, Freire developed his ideas to apply them in the local settings of Brazil and Latin America in the 1960s and 1970s, but his practices have since expanded and are used by educators in many countries. His ideas were introduced outside of Brazil in 1970 by his well-known book *Pedagogy of the Oppressed* and many fields use his problem-posing method of inquiry. Freire clearly stated that he had created a pedagogy, not a curriculum and because he focused on underlying philosophies rather than a specific curriculum, his ideas are highly transferable to other populations and scenarios. Disability may not have been part of Freire's original intent, but West (2014), for example, has

argued that Freire's *Pedagogy of the Oppressed* is the "best model for changing the lot of people with disabilities" in America (p. 11).

Freire's questioning method is frequently referred to as a humanizing pedagogy, whereas the opposite type of education in which students sit and memorize un-questioned facts doled out by experts is frequently referred to as a banking method. In Freire's conceptualization of traditional educational practice, experts simply deposit knowledge into novices, such that students are simply accounts to be filled—further dehumanizing people by treating them as containers, or things (Gottlieb & LaBelle, 1990). Although not part of his original work, an extension of this banking metaphor to students with ID/DD suggests that their exclusion from the general education curriculum indicates that they are not even viable containers that can be filled. This non-viable container idea aligns with the idea that reducing individuals to a single dimension (i.e. IQ; fixed intellectual capacity) negates the multiple dimensions of humans, limiting their ability to also experience societal opportunities and privileges by being reduced to and labelled in a deficit manner.

Bell (2013) noted that we need clear cut ways to define, analyze, and understand oppression. While other critical theories are available, and some overlap with Freire, the aspect of abject dehumanization experienced by individuals with ID/DD in the past and their organic lack of self-determination and self-advocacy skills (as part of the ID/DD diagnosis) makes Freire a very good fit to explore this phenomenon. Freire's ideas identify education as an essential component in human development, something that individuals with ID/DD have been denied for most of recent U.S. history, and his ideology provides a framework for applying his consciousness-raising pedagogy, which

he calls “reading the world,” and for identifying roots or systems of dominance and oppression which may be, in some ways, significantly different than dominance and oppression for other groups due to the ID/DD diagnosis that includes “significant limitations in intellectual and cognitive function and adaptive behavior as expressed in conceptual, social, and practical adaptive skills” (AAIDD, 2018).

In the book’s first chapter, Freire introduces the concept of humanization, upon which his belief in the importance of education rests. Humanization is the condition of both being human and becoming more human. For Freire, the condition of men is separate from that animals, in that humans are conscious of the world and have an objective relationship with it. Unlike animals, humans can step back and consider their lives and the world in which they live. Animals act instinctively, whereas humans can choose to act upon what they see and create change directed at themselves, at the world around them, or in both directions. This capacity to gain control over one’s life can be referred to as *agency* and developing the capacity to know oneself and be able to express this knowledge can be called gaining *voice*. In the process of gaining voice and agency, individuals can become subjects of the future that they envision for themselves rather than remain passive objects manipulated by the world around them.

On the other side of this task lies the oppressive forces seeking to prevent individuals from being and becoming human. For Freire, oppressors are those who create injustices and practice exploitation, oppression, and violence in ways such that others are denied the capacity to practice being and becoming and are thus dehumanized. When people’s knowledge of their situation is limited or controlled, and when they are denied

education that might allow them to take a more objective stance and gain control of their position in the world, oppression occurs.

Drawing on Freire's ideology, I used the following components for this study: (a) Freire's definition of humanity and his basic premise that all education should support the process of individuals in being and becoming more human, or *humanization*; (b) Freire's delineation between *oppressors* and *the oppressed*, including complex layers of both; and (c) the administrator's role, as *liberating educator*, working in solidarity with an oppressed individual or group to achieve liberation from oppressive forces. I consider administrators as individuals who join with their students in solidarity to work together for liberation from oppressive systems in which students with ID/DD have been pervasively denied access and inclusion in higher education.

### **Humanization**

Freire (1970/2013) said that "concern for humanization leads at once to the recognitions of dehumanization" (p. 43). This has been the historic plight of individuals with ID/DD in recent U.S. history. Individuals with ID/DD have been denied basic human rights and the opportunities to pursue their own paths and participate in their own humanization. For Freire, dehumanization was a state experienced not only by those who are being dehumanized but also by those who are responsible for creating dehumanizing circumstances. Therefore, only solutions that can free both the oppressed and their oppressors from being oppressive will result in humanization for both: "Only power that springs from the weakness of the oppressed will be sufficiently strong to free both" (Freire, 1970/2013, p. 44). Administrators serve in roles that may mitigate the roles of marginalized students and institutions that serve as gatekeepers to higher education for

individuals with ID/DD because of cultural norms regarding what higher education is and who should have access to it. Jones et al. (2015) concluded that postsecondary environments and ideologies either recognize individuals with intellectual disability as individuals worthy of challenge and opportunities for risk-taking and as individuals who are expected to contribute to communities in meaningful ways, or they view them as charity cases who rely on the generosity of others.

### **Oppressor/oppressed**

For Freire, the oppressors are individuals or systems that create injustices, practice exploitation, and oppress or do violence to others (dehumanize them). In the past, legally mandated practices excluded individuals with ID/DD from participating in the community through forced institutionalization and even forced sterilization (Kendregan, 1966; Rowlands & Amy, 2018). Nerney et al. (2017) encourage reflection on Thurgood Marshall's comments from the United States Supreme Court bench in 1985 regarding deinstitutionalization of individuals with ID/DD:

The mentally retarded have been subject to a lengthy and tragic history of segregation and discrimination that can only be called grotesque, fueled by the rising tide of social Darwinism, the "science" of eugenics, the xenophobia of those years. A regime of state mandated segregation and degradation soon emerged that in its virulence and bigotry rivaled, and indeed paralleled, the worst excesses of Jim Crow. Massive custodial institutions were created to warehouse the retarded for life. The aim was to halt reproduction of the retarded and nearly extinguish their race (p. 3).



At the individual level, widespread prejudices against individuals with ID/DD pervade society (Scior & Furnham, 2011). Less obvious forms of oppression include lowered expectations of individuals with ID/DD, and the lack of opportunities that results from those lowered expectations (McGrew & Evans, 2004). Additionally, higher rates of ID/DD occur in individuals from impoverished backgrounds. Low socioeconomic status contributes to malnutrition, culturally impoverished environments, and a lack of access to medical care, all of which can contribute to lowered cognitive development (Groce, et al., 2014; McCoy et al., 1994). Young (2015) has declared that “there is now ample documentary evidence to show that poverty—and the physical, intellectual, and emotional deprivations that go with it—can be a direct cause of mental retardation” (p. 418).

Larger societal changes not directly related to specific individuals can have an oppressive impact on a demographic group. Such is the case for individuals with ID/DD, who, prior to the industrial revolution, were more likely to be integrated within the fabric of society through useful roles that fulfilled individualized tasks (Kendregan, 1966; Shymen, 2013). Freire makes it clear that “there is a very radical difference between training and forming, it is not just a semantic question” (Freire, et al., 2014, p. 37). Education is “no longer defined as a form of self-development, individuality is reduced to the endless pursuit of mass-mediated interests, pleasure, and commercially produced lifestyles” (Giroux, 2002, p. 426). Standardized education creates workers to fill industry positions and commodifies individuality (Sleeter, 2012).

The preceding discussion can be seen within the general context of higher education where similar discussions take place particularly in the field of DE, in which

the effects of neoliberalism push against the stronghold of educational elitists to create a constant tension regarding education's purpose (Noddings, 2015) and who should have access to it. Students who lack college-ready skills are pushed by the needs of the workforce to go to college but are simultaneously pushed back by higher education and classified as non-college ready or academically underprepared. Students are thus seen as problems to be solved, rather than as individuals in need of support. Barefoot et al. (1999) responded to this by considering that the notion of "success" might need to be redefined and reassessed. Sleeter (2012) and Bensimon (2017) have pointed out that non-culturally responsive supports serve the purposes of the workforce or institutions of higher education rather than the personal growth and developmental needs of the student.

Freire called this non-personal, non-dialogical, and non-culturally responsive education the *banking method*. In the banking method, students serve as receptacles for information, accounts into which knowledge is simply deposited, rather than as individuals who construct a meaning of the world around them that proceeds from their personal experiences. Freire attributed a lower level of critical thinking skills to this type of education: "How can one be a critical mind if one is not able to create and recreate" (p. 38). Such education does not value individual strengths or provide a place for those opposed to or incapable of conforming to standardization. Given Shogren et al.'s (2015) explanation of contexts that recognize immutable characteristics of students (e.g., language, age, gender) and changeable factors (e.g., organizations, policies, attitudes), the banking method can be seen as a system that by remaining rigid and unchangeable either produces rigid and unchangeable students or discards those incapable of being processed in a rigid and unchangeable manner.

## **Educator/solidarity**

The administrators of PSE for students with ID/DD are those who stand in solidarity with students with ID/DD for access and inclusion on college campuses. These individuals' positions straddle their individual programs and the rest of the campus community. Explorations of administrator advocacy for students with ID/DD across campus programs and personnel may help tease out factors of systems or instances of oppression that require resistance and/or advocacy.

Best practices in the field of ID/DD education encourage several factors that administrators consider when advocating. The first factor, *person-centered planning*, refers to basing decisions on the achievement of goals that students with ID/DD make for themselves. The second, *supporting the development of self-determination in individuals with ID/DD*, means providing them with the skills to make decisions for themselves and to self-advocate. Freire (1970/2013) said that the state of being oppressed is not a “given destiny” (p. 44), and he elaborates on what he calls *false charity*, or support that “constrains the fearful and subdued” (p. 45). True support, or, solidarity, assists oppressed individuals to require “less and less in supplication, so that more and more they become human hands which work and, working, transform the world” (p. 45).

Adding urgency to the topic of inclusive PSE for students with ID/DD are the facts that students with ID/DD are highly vulnerable, experience heightened levels of social stigmatism, and are one of the most marginalized groups among individuals with ID/DD (Ali et al., 2016; Hall, 2005; Koh, 2004). One must address what might happen when students who report the highest level of abuse among the disabled community are included on campuses (Baladerian, 2013, Fisher, et al., 2013), particularly when such

abuse is exasperated by a marked lack of self-determination and self-advocacy skills (Grigal, et al., 2003, Field, et al., 2003). Other factors also contribute to relational problems for individuals with ID/DD. These include the inability to recognize behaviors related to ID/DD as distinct from other mental disorders, coupled with incorrect beliefs regarding the cause of ID/DD, ineffective resources for helping students with ID/DD, and a desire to distance oneself from individuals to avoid being stigmatized (Link & Phelan, 2001).

According to Sobsey and Calder (1999), vulnerability of individuals with ID/DD increases as participation in open social settings such as college campuses increases, and models for increased protection should be considered. As we invite these highly vulnerable students to our campuses, protecting them must become part of institutions' design. Williams (2008) stated that that diversity planning efforts are usually spurred by critical incidents, and that one of the first lines of response to a diversity issue is to increase the presence of the new demographic. In the case of students with ID/DD, this increase is already happening, and campuses must be connected to resources that can help them avoid abuse and harm to these highly vulnerable students.

### **Chapter Summary**

Students with ID/DD are coming to college in greater numbers, and research supports the benefits of these experiences. Liberating laws support participation in higher education and liberating benefits of these experiences are apparent. Ignorance, stigma, and academic gate keeping prevent students with ID/DD from accessing quality opportunities to develop personally, academically, and vocationally. The movement for inclusive PSE is built on concerned stakeholder advocacy and has not yet been

normalized in higher education. Administrators are in a position to advocate for students' access and inclusion on campuses, and access to their knowledge may provide a crucial bridge to establish inclusive policies and practices in higher education for more equitable access that can impact the learning of all students.

On the surface, this may appear to be an educational issue; however, research on PSE for students with ID/DD is situated in a gap that is particularly deep and complex (Thoma, 2013; Vaccaro & Kimball, 2017). Evidence of changing systems to normalize these programs does not yet exist, nor are there research-based suggestions for doing so. Grigal, Hart, & Lewis (2012) have stated that “the markers of progress may be misleading, as they reflect the potential for a new reality more than a current reality” (p. 4).

Inclusive PSE is an educational issue woven together with disability studies, diversity and multicultural studies, the rights of students to access and support, and human rights. Administrators are stepping up to the plate and doing an as-yet undefined job. Focusing a critical lens on the experiences and beliefs of those with a close look at the implementation of inclusive PSE for students with ID/DD can lead to a better understanding of the next step toward normalizing and ensuring these experiences. In gaining a deeper understanding of how administrators' roles support educational equity in higher education, we may gain a better understanding of what it means to be humanizing educators. As Darder (2017) has reminded us, “powerful teacher narratives offer examples of a living practice, a humanizing approach to teaching and learning” (p. ii).

### **III. METHODOLOGY**

#### **Introduction to the Methodology**

The purpose of this study was to explore the experiences and beliefs of administrators of postsecondary education (PSE) programs for students with intellectual and developmental disabilities (ID/DD). The questions guiding this naturalistic qualitative study were designed to gather information from a broad sweep of administrator's experiences and to provide data for both within-case analysis and cross-case analysis. The following questions guided the research.

Overarching RQ: How do the personal, professional, and educational experiences of administrators of PSE programs for students with ID/DD and their beliefs about the human growth and development potential of students with ID/DD impact their work in the field of inclusive PSE?

RQa: What are the personal, professional, and educational experiences of administrators of inclusive PSE programs for students with ID/DD?

RQb: What do administrators believe about the human growth and development potential of students with ID/DD?

RQc: How do those experiences and beliefs impact administrators' work in the field of inclusive PSE?

#### **Study Design**

In this study, I used naturalistic inquiry and a case study approach informed by the work of Guba and Lincoln (1985), Lincoln and Guba (1989) and Erlandson et al. (1993) to explore the experiences and beliefs of administrators of inclusive PSE programs for students with ID/DD. Naturalistic inquiry is a good choice for exploring novel,

complex phenomenon, and for constructing involving an exploration of both experiences and beliefs and the relation participants offer between their experiences and beliefs and their administrative roles facilitating inclusive PSE for students with ID/DD which has a distinctive social justice mission. The emerging role of these administrators is complex and spans types of work done in several different fields, including K–12 special education, higher education, community engagement, and social work (Bumble et al., 2019) with the social justice component of providing access and equity for a student population with a history of exclusion, marginalization, and other injustices (Nerney et al., 2017).

Within the naturalistic paradigm, findings are created, not discovered, and data collection and analysis occur in concurrent, integrated steps so that deconstruction and reconstruction happen throughout the study allowing for deep thematic exploration and holistic narrative development (Erlandson et al., 1993). Constructed meaning between participant and researcher requires researcher transparency regarding positionality and reflexivity, particularly regarding values and beliefs. Prolonged exposure to participants provides the time needed to establish a deep, mutual understanding between the researcher and the participant, and for deepening insights to develop.

The naturalistic approach requires prolonged exposure which allows for relationship building and provides the extended time and flexibility necessary for reaching deeper meanings. Within the naturalistic paradigm, findings are created, not discovered, and data collection and analysis occur in concurrent, integrated steps so that deconstruction and reconstruction happen throughout the study allowing for both deep thematic exploration and holistic narrative development (Erlandson et al., 1993).

Erlandson et al. (1993) used a metaphor to explain the deep exploration done in naturalistic studies, saying that a “whole cloth” approach is preferable to examining one small detail in isolation without context: “By closely examining one small corner, the nature of the entire piece can be determined” (p. 11). Such a focused look with attention to the contextualizing features emphasized by naturalistic inquiry is a good fit for addressing Freire’s admonition to dig deep into areas of oppression that contain layered structural relations between the oppressed and their oppressors, and Yin, (2009, 2016) stated that case study is a good fit for complex, highly contextualized studies.

In addition to building a critical understanding, this study is intended to address a gap in the literature by exploring administrators’ experiences and qualifications for filling their novel roles. Not only is there a gap regarding administrators’ experiences and qualifications for developing inclusive PSEs, there is a need to explore this topic critically, because the administrator’s role involves breaking down barriers to inclusion for a traditionally marginalized population.

Naturalistic inquiry presented as case studies provided a means for obtaining rich information from participants and also for maintaining a structure for cross-case analysis (Erlandson et al., 1993). The prolonged exposure between researchers and participants required by Naturalistic inquiry provided a framework for the co-construction of shared knowledge (Erlandson et al., 1993; Guba & Lincoln, 1985). Verification in the study came from frequent member checking, data triangulation, researcher reflexivity, and transparency, all of which helped to establish research standards while accounting for multiple realities (Guba & Lincoln, 1989). I first constructed personal, single-case stories using was Seidman’s (2006) in-depth interview process—a series of three, 60-minute,



semi-structured, open-ended interviews with each of nine participants and then applied a critical lens derived from the educational philosophies of Freire during analysis to dig deeper into the social injustices students with ID/DD face. The critical lens informed both the construction of single-case stories and the development of cross-case themes.

The cases were bounded by the administrators' experiences and contextualizing factors, which included types of programs administered (e.g., 2-year, 4-year, CTP status), types of hosting campuses (e.g., community college, private or public institution), and general geographic locations. Artifacts collected to support and verify administrators' stories and details about their programs included CVs, program information, and information posted on websites. No identifiable data are provided in this report, but sample program literature can be found in Appendix A.

### **Participants**

I conducted the study with nine administrators of inclusive PSE programs for students with ID/DD. To solicit participants from this niche higher education area, I received permission from the organization Think College to send a recruiting email to their listserv of program administrators. With just 279 programs in the U.S. (Think College, 2019), the pool of PSE programs is not large, and they do vary greatly in the amount of inclusion they offer their students and the range of choices students are given in the programs to design a course of study based upon exploration and choice. Fifteen administrators responded to an initial email solicitation which included a description of the study. Of these, nine were selected based on criteria that helped to obtain maximum variation. Participants were selected who represented institutions with different types of programs, as well as institutions from an array of locations. Variations in programs

included the amount of time students spent only with students in their program, whether or not they took regular courses with other students either for credit or as auditors, the availability of on-campus housing, and program length. Most programs were recently established, whereas one was over 30 years old. The programs were located on different types of campus (2-year, 4-year, public, private), and in different geographic locations across the U.S. I did not select administrators of programs that were strictly vocational (i.e. offering only culinary or childcare certificates) or programs that were not located on college campuses, because the study's emphasis is on inclusive PSE programs that provide maximum student inclusion, choice, and flexibility on college campuses.

Such purposive sampling, according to Erlandson et al. (1993) enables insights about the topic to emerge by appropriately representing a wide range of experiences and maximizing information gathered within that context which also enables insights about the topic to emerge. In addition to providing sample variation, purposive sampling that includes case studies with strong boundaries can allow a deeper exploration and understanding of complex phenomenon that can help raise readers' awareness of a study's focus and contributes to cross-case analysis (Lincoln & Guba, 1989; Mertens, 2015; Yin, 2016). Boundaries for each case were the administrator and their practices within their program. Purposive sampling in this study was especially appropriate because naturalistic inquiry is not primarily intended to generalize findings to a broader population, but to "maximize discovery of the heterogeneous patterns and problems that occur in the particular context under study" (Erlandson et al., 1993, p. 82). According to Plotner and Marshall (2015), a study design that allows for both within-case analysis and

cross-case analysis is needed at this time to move the field beyond isolated institutional data collection and can serve as a foundation for program development.

### **Participant Safeguards**

In accordance with institutional IRB requirements, participants were mailed consent forms that described the nature of the study and the time commitment required. After consent forms were returned, participants were sent a list of preliminary questions and asked to furnish a copy of their resume or CV as well as any program information readily available. Upon receipt of the requested information, interviews were scheduled beginning in January 2019. A copy of the IRB protocol and consent letters can be found in Appendix C.

All data were stored on password-protected devices, and de-identified transcriptions and reports were generated. Participants selected pseudonyms for themselves, or we worked together to find agreeable pseudonyms. Throughout the interview process, confidentiality was maintained.

### **Participant Description and Synopses**

Table 1 provides an overview of the participants' ages, gender, years working with individuals with disabilities, and their formal educational training. Below the table narrative synopsis of each participant are provided for quick reference as participants are identified in the study. Focus cases of Daphne, Ethel, and Lori are included in the findings chapter. More complete synopsis of all the participants are located in Appendix B.

**Table 1**  
*Participant Description Summary*

Participant	Gender	Age	Years working with disabilities	Formal Education
Daphne	F	40s	35	BS, Rehabilitation services MS, Rehab. counselor education
Ethel	F	40s	22	BS, Psychology MS, Communications PhD, Cultural foundations of education
Lori	F	60s	42	BS, MS, PhD, Special education
Maggie	F	60s	30	BS, MS, Applied psychology AS, Disability support
Emelia	F	30s	15	BS, MS, PhD, Special education
Jane	F	50s	35	BS, Special education
Javier	M	60s	35	BS, Social work MBA Ph.D. Human resources and special education
Rachelle	F	30s	12	BS, Biology, MS, Social work PhD, Special ed, program administration
Bobbie	F	30s	12	BS, Psychology MS, Behavior analysis, MEd, Special ed. PhD, Special ed.

*Note.* Years working with disabilities are approximate and include volunteer and professional work experiences, but not personal experiences, although personal experiences and volunteer work may overlap.

**Daphne**

Daphne, a woman in her early 40s, was instrumental in the design and implementation of an inclusive program that began accepting students in 2016 at her 2-year community college. Daphne has been at her institution for over 13 years, and she currently holds a dual role—as an associate professor and disability learning specialist, and as the program administrator for the inclusive PSE program on her campus. Daphne has a bachelor's degree in rehabilitation services and a master's degree in counselor education with an emphasis on rehabilitation counseling. Prior to her current position, she held positions as a disability learning specialist and an assistive technology coordinator at other institutions of higher education. She has also been a practicing rehabilitation therapist.

Daphne was born with cerebral palsy, and her entire life has been spent around individuals with disabilities. Although she did not have a cognitive disability, she was placed in special education during her elementary school years, and she participated in the Special Olympics.

**Ethel**

Ethel, a woman in her 40s, was hired by her PSE program when it was implemented at a 4-year private institution in 2007, though she was not part of the program's original design and implementation team. She has a bachelor's degree in psychology, a master's degree in journalism and mass communications, and a PhD in cultural foundations of education. With 25 years of experience working with children and young adults with ID/DD in a variety of capacities, she came to her work tangentially

when she was introduced to this population during summer employment as a student in college.

Ethel was originally hired to be program coordinator, a position that has changed over the years. Currently she is in charge of curriculum design and instruction. In this role, Ethel seeks to develop methods for helping students gain voice and agency using nontraditional methods, particularly artistic and creative expression including poetry and theater. Ethel reported personal connection to disability in her family and has experienced disability personally. Ethel also identifies as a biracial woman.

### **Lori**

Lori, a woman in her 50s, was instrumental in the design and implementation of the inclusive program at a public 4-year institution. Conversations to begin the program were initiated by a local school district transition coordinator in 2007, but the program did not begin accepting students until January 2016. Lori's role was to help gather many pieces together to make the program happen; she hired and designated personnel to cover curriculum design and employment coaches, and she helped establish program policies, including course plans. Lori has a bachelor's, master's and PhD in special education.

Lori reported that she had no personal proximity to disability or diversity. She became interested in working with people with disabilities through a volunteer opportunity she had in high school. Working with this population resonated with her from the start, and she continued working in the field of special education from that point on. With over 30 years of experience in special education at multiple levels, she recently retired from a tenure-track position after 23 years of teaching and supervising special

education majors. She frequently mentioned that she felt lucky to have fallen into a career that she loved.

### **Maggie**

Maggie, a woman in her mid-60s was hired part-time in 2016 to replace the woman who designed and implemented her PSE program in 2010. Her position became full-time in 2018, and her current title is Program Director. Maggie's program is a bit different from most of the others because it consists of a high school transition component and a community vocational support program, which are run by two different staff members and serve two different purposes. Maggie's role includes coordination among different partners, the college, and community employment internships.

Maggie came to the field of disability support later in life after her third child was born medically fragile and was later diagnosed with autism and ID/DD. Maggie left a successful career as a consultant for major corporations to care for her child. She drew upon applied psychology and anthropology to design better workspaces for employees. Her bachelor's degree is in psychology, and her master's degree is in human factors, a type of applied psychology used for design and analysis. After her daughter grew up, Maggie returned to school to get an associate's degree in disability support; while she was obtaining her associate degree, one of her disability studies professors, who had designed and implemented the program on her campus, approached her to administer the program.

### **Emilia**

Emilia, a woman in her mid-30s, was born in Mexico. She came to the U.S. with her family when she was in middle school. She was instrumental in designing and

implementing the inclusive PSE program on a four-year campus. Planning for the program began in 2015 with a new colleague who had come from an institution that had an inclusive PSE program, and, coincidentally, she was advising a doctoral student who was doing research on inclusive PSE programs at the same time. The program opened in 2018.

Emilia holds three degrees in special education and has experience in working with students with intellectual disabilities in U.S. schools as well as in Mexico and Ecuador. She teaches courses in diversity in special education, research, curriculum, and assessment in special education, and teaching in inclusive classes. Her research focuses on addressing disproportionality in special education through the use of culturally responsive practices and pedagogies. Emilia also has experience in teaching bilingual special education. She has a personal connection to disability, and she also experienced middle and high school as an English language learner.

### **Jane**

Jane, a woman in her early 50s, was instrumental in the design and implementation of the inclusive program at a public 4-year college, which began accepting students in 2010. Jane first began working with individuals with disabilities at a summer camp when she was in high school and continued working with students throughout her career in a variety of educational settings. She has a bachelor's degree in special education with considerable professional development subsequent to that, including many additional courses at the master's level.

Jane began working in the disability field in high school but was originally undecided in her college major until her advisor connected her prior work in disability



with studies in special education. Jane mentioned proximity to disability in her family (mental illness), and she related that she was from a rural, low socio-economic background and was the first in her family to attend college. Throughout her 25-year career in special education, Jane envisioned postsecondary programs that would extend the education students that receive in K–12 and provide them with lifelong support.

### **Javier**

Javier, a male in his 60s, was instrumental in founding, designing, and implementing the inclusive PSE program at a 4-year public institution, which began accepting students in 2014 after several false starts beginning as early as 2002. He has been a professor of special education at his institution since 1999 and currently holds the title of Professor. He has a bachelor's degree in social work, a master's degree in business administration, and a Ph.D. in education and human resource studies with a concentration in special needs education. Javier teaches courses in the psychology of students with disabilities, psychological aspects of individuals with disabilities, applied foundations of contemporary special education, and multicultural aspects of people with disabilities.

Prior to his university position, Javier described significant work experience in group home management, independent living, and employment services for people with ID/DD and he also served on several disability advocacy boards. His education was spurred by his work experiences with individuals with ID/DD and he continually sought better solutions to their social, work, and housing needs. This desire led him into personal and professional relationships with Wolf Wolfensberger, the founder of Social Role Valorization, and with other lead thinkers in the field and he also had the opportunity to

study at the Highlander Research and Education Center where the Civil Rights movement was formed. Javier has personal experiences with ID/DD through a close relative and describes himself as a privileged, white male.

### **Rachelle**

Rachelle, a woman in her early 30s, has 12 years of experience working in inclusive higher education. Her program, which began accepting students in 1982, is located at a 4-year private institution and has evolved to become an entire department on campus with its own alumni center. She holds a bachelor's degree in biology, a master's degree in social work, and a PhD in special education with a focus on program planning, administration, and evaluation.

Rachelle began working at her current institution 12 years ago as a resident assistant for the inclusive program. Eventually, she became the director of resident life, and she was also instrumental in developing the program's alumni association, which provides lifelong support for individuals who go through the program. Her current role is as director of academics, innovation, and inclusion. In this new role, she focuses on working with local school districts to form partnerships and create connections and scholarships for students with ID/DD who are from low socio-economic and minority backgrounds. Rachelle mentioned that she had a close relative who probably had undiagnosed autism, but other than that, she did not have much experience with people with disabilities or diversity until she purposefully sought out those experiences when she considered going into what she referred to as a "helping field."

## **Bobbie**

Bobbie, a young woman in her early 30s was not part of the design and implementation of the dual-credit PSE program at her 4-year public institution, but she was hired to administer it from the day of its opening in 2013. Prior to that, Bobbie worked in a variety of jobs including public high school special education, in-home direct care, and behavior therapy. Bobbie earned a BS in psychology, an MS in behavior analysis, and an MEd in special education for severe disabilities K–12. She is a board-certified behavior therapist and is certified for K–12 special ed.

Bobbie's role includes coordinating students in high school with college courses, and she also teaches disability studies. She is currently thinking about returning to school for a third master's degree in public health to help her solve some issues that she has seen with regard to the emotional well-being of students with ID/DD. Bobbie's goal for her program is that it should mirror any other typical college experience, and she wants the students in her program to act like any other college-age student and have the same types of experiences, including exploring life and making mistakes in a safe environment.

Bobbie was diagnosed with AD/HD during her doctoral program. She also mentioned that she experienced stigma as a person from a low-income, single-parent home whose friends were all from nuclear (two-parent) families with access to better resources and support.

## **Program Descriptions**

Table 2 provides a side-by-side overview of the programs and their hosting institutions. This overview includes comprehensive transition program (CTP) status, whether or not students take classes for credit or audit, and what types of classes are

available to them. Employment opportunities during the programs are noted, as well as employment outcomes, housing information, and the percent of time students spend with only students in the program, which indicates a less inclusive setting but may be appropriate for the task or topic addressed. The table also includes data on the hosting institution, geographic location, and numbers of graduate and undergraduate students.

**Table 2**  
*Programs<sup>1</sup> and Institutions<sup>1,2</sup>*

Participant	Program Description	Hosting institution	Notes
Daphne	This program is a CTP. Students take traditional college courses for credit or audit, and continuing education. 72% of students have paid work while attending the program. 52% of students have paid work after exiting program.	2-year, public community college Located in the mid-Atlantic region of the east coast 7,109 undergrads	Housing is not available on campus. Students spend less than 25% of their time only with other students in the program.
Ethel	This program is a CTP. Students take traditional college courses for credit or audit, and continuing education. Employment information not available, but opportunities for employment, internships, and volunteering are available.	4-year, Private not-for-profit Located on the east coast 900 undergrads 126 grads	Housing is inclusive on and off campus. Students spend less than 25% of their time only with other students in the program.
Lori	This program is not a CTP. Students take traditional college courses for credit or audit. 50% of students have paid work while attending the program. 100% of students have paid work after exiting program.	4-year, Public college Located in the southeast 24,376 undergrads 5,396 grads	Housing is not currently available. Students spend 50-75% of their time only with other students in the program.

Table 2. Continued

Maggie	This program is a CTP. Students take traditional college courses for credit or audit, and continuing education. Dual credit program, employment information not available	2-year, public community college Located in the mid-Atlantic region of the east coast 12,273 undergrads	Housing is not available on campus. No other information is available.
Emelia	This program is a CTP. Students take traditional college courses for audit. Employment information not available, but opportunities for employment, internships, and volunteering are available.	4-year, Public Located in the northwest 26,098 undergrads 5,380 grads	Housing is not currently available. Students spend 25-50% of the time only with other students in the program.
Jane	This program is a CTP. Students take traditional college courses for audit. 94% of students have paid work while attending the program. 80% of students have paid work after exiting program.	4-year, Public college Located in the southeast 9,880 undergrads 903 grads	Housing is inclusive on campus. Students spend less than 25% of their time only with other students in the program.

Table 2. Continued

Javier	This program is a CTP. Students take traditional college courses for credit or audit. 100% of students have paid work while attending the program. 100% of students have paid work after exiting program.	4-year, public liberal arts institution Located in the mid-Atlantic region of the east coast 6,779 undergrads 1,002 grad/doctoral	Housing is inclusive on campus. Students spend 0% of their time only with other students in the program.
Rachelle	This program is not a CTP. Students take traditional college courses for credit and audit. 24% of students have paid work while attending the program. n/a % of students have paid work after exiting program.	4-year, Private not-for-profit Located in the mid-Atlantic region of the east coast 2,208 undergrads 2,630 grads	Housing is provided in special settings in dorms, sometimes with students outside of the program. Students spend about 75% of the time only with other students in the program.
Bobbie	This program is a CTP. Students have dual enrollment and take traditional college courses for credit or audit. 20% of students have paid work while attending the program. 30% of students have paid work after exiting program.	4-year, Public Located in the mid-Atlantic region of the east coast	Housing is not provided. Students spend less than 25% of the time with other students in the program.

<sup>1</sup> Data obtained from Think College (2019a).

<sup>2</sup> Data obtained from institutional websites and the National Center for Education Statistics (2019). Data from institutional websites are not cited, in order to maintain anonymity.

The development of PSE programs is highly independent because programs develop in unique ways with different sources of funding, different campus types of campus support, and different types of community connections including disability support services and employment and internship opportunities. To help contextualize the focus cases presented in chapter four, I've provided in-depth descriptions of Daphne, Ethel, and Lori's programs as they described them.

### **Focus Case Program Descriptions**

Daphne's PSE program is situated at a public community college in a mid-Atlantic state, within an area that is not particularly diverse. The program began accepting students in 2016. It originated in the college's Office of Disability Services (ODS), in response to a need to better support students who were admitted but did not continue their education because they had additional needs that traditional supports did not address. The program began through Daphne's discussions with community and education agencies. The program anticipated many areas of students' needs, and from its inception it included a design team, an integration team, and an advisory team. The program is well received on her campus. It is unique in that it provides three different levels of certification based on different amounts of courses taken for credit or audit. Each level also provides different amounts of student support. Daphne's program is included under academic affairs.

Ethel's PSE program is located at a 4-year private institution in a central east coast state; the institution has a diverse student body. Program planning began in 2005, with the first students admitted in 2007. The program originated in conversations



between local providers and community members, which established a need and desire for a PSE program. While attending a community meeting, the university's chancellor became aware of this discussion and subsequently decided that the university should have such a program on campus. The program started as a 2-year sequence and quickly grew to 4 years at students' request. This program focuses mainly on developing students and helping them gain voice and agency and providing an opportunity to explore career and life options. It constitutes a department within the university's office of research and engagement, with certificates issued by the provost.

Lori's PSE program is located at a public 4-year institution in the southeast. In 2007, individuals from the local school district approached the institution to start a program, and it opened in 2016. Lori's program has a strong structure with clearly delineated objectives and outcomes; designated staff fulfill specific roles. The program has developed a series of courses designed specifically for PSE students, but these courses are available for any student to take and include topics such as first aid and financial literacy. Lori's program is the only program examined here that is seated within an institution's special education department on campus.

### **Artifacts**

Specific artifacts were collected to verify data and provide additional context. These included administrators' CVs, program documentation, and information from institutional and program websites. The CVs served to verify participants' stories regarding their educational and professional experiences. Program documentation and program websites served to verify participants' descriptions of their programs. The

websites of the institutions hosting the programs enabled both verification of data (e.g., data from interviews) and provided additional information for contextualization (e.g., institutional type—public vs. private, 2-year vs. 4-year; school’s size and location; degrees offered—bachelors, masters, doctoral). Program and institutional data were further verified using the National Center for Education Statistics (NCES, 2019) database and the Think College website (2019). Table 3 provides an overview of artifacts collected.

**Table 3**  
*Artifacts*

Participant	CV or Resume	Program Documents	Additional Documents	Website information
Daphne	Yes	Referred to website	No	Yes
Ethel	Yes	Yes	No	Yes
Lori	Yes	Yes	No	Yes
Maggie	No	Yes-obsolete info	No	Yes
Emilia	Yes	Referred to website	No	Yes
Jane	Yes	Referred to website	No	Yes
Javier	Yes	Degree audit CTP application	Organizational chart Articles	Yes
Rachelle	Yes	Yes	Yes – mailed a huge information package with DVDs, fliers, and forms	Yes
Bobbie	Yes	Referred to website	No	Yes

### **Data Collection**

I began my data collection in January 2019. Data collection included a total of 1,620 hours of recorded interviews and artifacts collected from each program, which

included program information supplied by the participants and publicly searchable program and hosting institution data.

## **Interviews**

Interview data were thus gathered using Seidman's (2006) three-part interview process. The first two interviews were focused, consisting of predetermined open-ended questions, with the initial interview eliciting personal histories including administrators' personal, professional, and work experiences. The second interview gathered program information, including stories of how programs were designed and implemented, salient program features, and student successes and problems. These two interviews followed a designated protocol (see Appendix D). The third interview, constructed individually from each participant's prior two interviews, served as a reflective time to allow participants to consider how their prior experiences impacted their approaches to inclusive PSE. This interview method, according to Seidman (2006), "is a powerful way to gain insight into educational and other important social issues through understanding the experience of the individuals whose lives reflect those issues" (p. 14). Seidman considers this "in-depth, phenomenologically based interviewing" (p. 15), and it aligns with the naturalistic approach's requirement of prolonged exposure to develop rapport and minimize social distance.

The interview questions explored participants' awareness of critical issues related to structural, systemic, or ideological barriers encountered in their work. The third interviews served as member checks. Follow-up emails were also used subsequently for member checking or for gathering additional information. Emilia's participation was especially valuable because of her expertise in special education, her role as a primary

program designer and implementer for the program at her institution, and her awareness of Freire's educational philosophy and personal focus on educational equity and access. Data were also triangulated through discussion with other colleagues—particularly the discussion of one case, which stood in stark contrast to the rest.

All interviews were held via phone. The first two interviews occurred one week apart and were used identical interview protocols. The third interviews took place approximately three weeks later after data analysis of interviews one and two allowed for the unique construction of third interviews for each participant. Third interviews followed up on individual participant themes, such as having a personal disability story or a strong social justice acuity. Third interviews also served to bring themes from one participant to another which prompted responses to expand to themes that were developing in other cases and helped develop a deeper understanding of the cross-case themes with input from several participants rather than one. After recording the interviews, I sent them to a transcription service and then listened to them repeatedly while making corrections to the transcriptions.

### **Artifacts**

Each participant sent me program materials they had access to including program brochures, course outlines, program guides, and application materials. I also sought program and hosting institution information from online sources to verify and supplement information provided by the participants. Sources for online information included college websites, national clearinghouses on higher education, and the Think College website.

## **Data Analysis**

I began data analysis from the beginning of data collection using a constant comparative analysis informed by Glaser (1965). In this method, analysis begins with the first data intake and continues throughout the research process. Initially, I used a software program, Quirkos, to help sort large quantities of data and to search for In Vivo codes (Miles et al., 2014). In Vivo coding is a quick way to code data by noticing repeated phrases, word use, emotional language, and other distinctive features that invite further analysis. These data provided a list of level one codes which were categorized into four areas; critical, support, data that indicated a topic could be thought about as either supportive (positive) or oppressive (negative) for students, and data that indicated a topic was always oppressive (negative) for students (see Appendix E).

Next, I used the qualitative software to facilitate data chunking. I found stories and chunks of data clustered around a priori themes and themes derived from my research questions and conceptual framework. Chunking, a term used to describe holistic coding (Hedlund-de Wit, 2013) assisted with the identification of participants' top themes (see Appendix E for examples). Through data-chunking, I saw codes develop into themes as they pertained types of administrator experiences which expanded from work experiences, personal experiences, and educational experiences to include disability experience, identity development, powerful moment, moment of insight, and others. These developing themes within participants stories served as building blocks for individual narratives and also supplied themes for cross-case analysis.

For example, Daphne had many data chunks around the term “disability” that connected to her own experiences rather than her work or education. Daphne had

mentioned her own disability well before my interview question asking; “do you have or identify as disabled or diverse in anyway?” For Ethel, data chunking hinged around her strong emotional reactions to injustices. These emotional reactions were evident as she discussed every aspect of her life, personal, professional, and educational. Examining these data chunks helped me to determine that her strong emotional reactions were part of a theme woven through her life as she pursued social justice in her life, inwardly through critical self-reflection and outwardly by creating equitable practices for her students.

Maggie frequently stated that she felt inadequate regarding her contributions to inclusive PSE was very apologetic for her lack of knowledge, yet, demonstrated competence and knowledge in her prior professional career for which she was trained, and in her disability assistance career for which she was not professionally trained, but had gained experience through having a daughter with ID/DD. Examining this tendency for apologizing led me to consider her age (she was older), the reason she entered the field (had a child with ID/DD), and I further contextualized her earlier (confident) work period with the fact that she had done trail blazing work for women in the field before giving up her work to care for her disabled daughter. Maggie repeated several times that she was a successful woman “in a man’s world.” Within-case construction continued in the same manner for all the cases.

Next, I looked to a priori themes derived from my conceptual framework such as critical language and social justice awareness to create critical codes with which to analyze all the cases. Using this method, I categorized my level one codes into three dominant categories (a) participants’ use of critical language, (b) participants’ use of terms such as “experience” or “perception,” and (c) participants’ beliefs. Some

participants indicated critical knowledge by employing terms such as “pow” and “agency” or “bias” and “prejudice” other participants expressed an understanding of these critical components; however, they lacked a critical language to describe their experiences. For instance, Daphne stated “I’m fumbling with my words....I don’t like the words we use to describe these things.” Ethel noted that she felt injustices emotionally before developing proper critical language with which to address injustices.

In some instances, participants made the connections between their experiences and praxis and valued their experience as a source of their knowledge. For instance, Daphne made the statement “I’m only one individual with one perspective and one set of experiences,” and Emelia connected her experiences to her motivation to work with students with ID/DD stating; “when I was able to experience working with students with disabilities ... I fell in love with working with that population specifically.”

Beliefs and values were occasionally brought up directly by the participants even though I purposefully did not ask this question directly. As noted in the description of my own positionality, my approach to exploring beliefs in this study, which included operationalizing beliefs, was purposefully exploratory and emergent. Each time a participant initiated the use of the word belief or value, I carefully studied surrounding contexts to expand my own understanding of how beliefs might be portrayed, and I considered instances when beliefs were implied but not openly addressed. Javier, for example, brought up beliefs and values on his own when discussing a story about having witnessed an abusive situation involving a woman with ID/DD. He connected this incident with the solidification of his own values and beliefs regarding how individuals

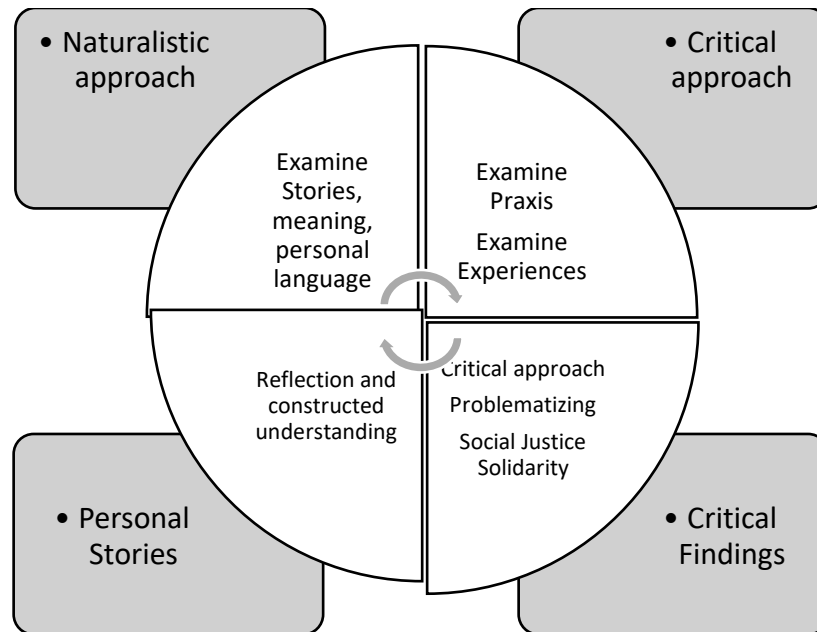
with ID/DD should be treated and discussed his beliefs succinctly, having developed them purposefully over time.

By following the single word beliefs in Javier's story, it was possible to make the connection that beliefs come from different kinds of experiences and that beliefs are not always stated explicitly but can imply a motivation for a following action. I triangulated this finding with a research professor in disability studies by having her code an interview and comparing her analysis with my own. Her coding aligned with my own and included observations such as personal experience impacts belief, personal belief impacts education choice, personal belief impacts educational path, and personal experiences lead to certain beliefs in disability related to programs and terminology. This examination helped to construct the definition of beliefs as knowledge. Similarly, analysis of administrator descriptions of student growth and student oppressions helped build the second construct of beliefs which was attitudes.

Data analysis continued recursively, with consideration of overarching themes (e.g., language use, experiences, beliefs), individuals' dominant themes (e.g., disability, identity, education, and work), as well as study design, research questions, and conceptual framework. Thus, a general theme such as education began to revolve less around level of degree attainment and education discipline such as special education or sociology and was replaced by specific knowledge such as knowledge of oppression and knowledge of critical self-reflection (conscientization). This led to hypotheses regarding salient features within participants' stories and overarching categories for cross-case analysis.



While normally associated with validity and trustworthiness, peer debriefing with professional colleagues both within my department and with professionals in disability studies provided additional insights for conceptualizing the data, particularly with regard to the one divergent case, and forced me to reconsider my positionality and objectivity as a researcher and to recalibrate when necessary. Recalibrating included stepping away from the data and recommitting to the selected analysis criteria. Member checking during interviews and through subsequent emails confirmed my interpretation of data. Figure 1 illustrates how the naturalistic study design and critical conceptual framework served as guides for cycling the data through the study's two main research focuses: administrator's personal experiences and critical awareness.



**Figure 1**  
*Framework for Analysis*

Because the study went beyond asking what are the experiences of administrators to how those experiences shape their practices, data were subjected to several rounds of analysis, and themes were developed and compared within cases and across cases to

determine when they were relevant to all cases or when they ceased to be relevant beyond one or two. Some categories expanded: disability expanded to include other types of diversity or stigmatizing or marginalized experiences. Some categories collapsed: beliefs narrowed to a simpler concept, defined as a “belief in the ability of students with ID/DD to grow and develop.” After considering all the categories in conjunction with all the differing experiences, four themes became the focal point for analysis.

1. Beliefs: Administrators’ beliefs about the human growth and development potential of students with ID/DD.
2. Knowledge of oppression: Administrators’ comprehension of experiences that limit the growth and development of students with ID/DD.
3. Conscientization: Administrators’ personal experiences with disability or diversity.
4. Praxis: Administrators’ responses to knowledge of experiences that limit the growth and development of students with ID/DD (praxis).

### **Positionality**

Throughout the entire process of this research from planning through final reporting, I considered my own positionality as it impacted the study. The researcher’s reflexivity is paramount in naturalistic inquiry (Erlandson et al., 1993), and the researcher acknowledges up front the roles that prior experiences, beliefs, and assumptions bring to the study. Here I provide a brief description of my own positionality and how those characteristics contributed to my interest in the study’s topic. A more complete description of my own disability story can be found in Appendix F.

As the daughter of a parent with a significant physical disability, I was rather young when I developed a sensitivity to the subtle, pervasive needs of individuals who have trouble in navigating the physical environment. My mother was actively engaged in disability support groups in Syracuse, NY, during the 1970s, and she and her friends with disabilities taught me to suspend judgement and emotion when offering my able body as a means of support while the individual with a disability chose how to navigate the environment and meet their needs.

When I had the opportunity to work with individuals with ID/DD as the music, drama, and spiritual instructor at a residential facility, I quickly learned that as different as each of the residents was with regard to mental and physical capabilities, each person was interested in doing fun and engaging activities, learning new songs and dances, and engaging deeply through conversation and study in any topic encountered. I learned that reading ability was not connected to thinking ability, and that coordination was not connected to joy in movement. Throughout this experience, I felt a growing desire to expand opportunities for individuals with ID/DD who faced very limited opportunities due to their living circumstances and lack of being in control. Being directly involved with individuals with ID/DD helped remove barriers to my understanding many of the complexities surrounding work with ID/DD, which can be confusing and perplexing to the uninitiated.

My reflexivity related to beliefs as a research topic was a significant factor in selecting my approach, which was predominantly emergent. This emergent approach to the conceptualization of beliefs aligned with my inductive research approach, but I also had personal reasons for taking it. Given the perpetually dehumanizing treatment of

individuals with ID/DD, I was afraid to delve into literature discussing whether individuals with ID/DD could be classified as humans. Such dehumanization of individuals with ID/DD is contrary to my own core beliefs, which can best be summed up with what Schweitzer (1979) refers to as having a reverence for life. I also come from a Russian Jewish family with ancestors who came from a small village where the entire Jewish population was annihilated during the Holocaust (Rothstein, 1999). The question just under the surface regarding the basic humanity of individuals with ID/DD, a question not so far-fetched given their recent and continuing history of abuse, neglect, and marginalization, was not one I could bring myself to ask outright.

In my search for administrators' beliefs, I was not looking for a deep, philosophical answer, yet one of my main assumptions in taking a critical approach to my topic was that some type of core belief in the humanity of people with ID/DD propelled their work, and that this work was part of a historical movement toward the inclusion of people with different abilities and away from the historic oppressions detailed earlier. Additionally, I recalled the unexpected ways in which my work with people with ID/DD often pushed my own beliefs into the forefront of my thinking, making me conscious of beliefs in a way I had not known before working with such a vulnerable population. Often, I was caught off guard by the deep connections I felt while encountering the largest spark of humanity from a glint in the eye of the most frail and infirm individuals.

So deeply entrenched were my own assumptions, that I decided to ask no questions directly related to beliefs during any of the interviews. Would beliefs surface as administrators spoke of their work? Was the story of their beliefs part of their motivation, and in what ways did their beliefs become evident? What types of beliefs would surface,

and what beliefs were important for supporting inclusive PSE? I was so afraid of putting my own spin on beliefs at the beginning of my research that when asked the question “how will you operationalize beliefs?” I simply responded with a question mark, trusting that the research would help fill the blank.

My own experiences and beliefs, coupled with my knowledge of access and support in higher education, provided a foundation for this study. I felt a sense of mystery as I approached each of my participants’ experiences regarding their work, and I used both my prior knowledge from working with individuals with ID/DD (emic perspective) and my ignorance (etic perspective) as needed to foster deeper inquiry and gain access to my participants’ experiences and insights.

### **Trustworthiness**

Erlandson et al. (1993) stated that measures of trustworthiness in naturalistic inquiry are not parallel to those in traditional paradigms, but “spring from the naturalistic paradigm itself.” Naturalistic inquiry accounts for the social construction of meaning, the phenomenological focus of the study as a context in which participants’ experiences are reconstructed, as well as naturalistic inquiry’s interpretive nature (Erlandson et al., 1993). In naturalistic inquiry, internal validity is established using several measures.

### **Prolonged engagement**

The first measure, prolonged engagement, helps the researcher build trust and rapport with participants. Although I was not physically present at each of the nine campuses due to time and budget constraints, I minimized social distance and established trust and rapport by (a) demonstrating that I was knowledgeable about working with students with ID/DD, (b) demonstrating that I was interested in their unique experiences

and asking follow-up questions encouraging deeper responses, and (c) sharing stories about myself that demonstrated relatable experiences.

### **Persistent observation**

A second measure for establishing internal validity consists in persistent observation, which refers to the depth of the information gathered. The third interview in Seidman's (2006) three-part interview protocol is specifically designed for deeper probing of data gathered in the preceding two interviews. In this study, the first interview focused on specific aspects of participants' life experiences, including professional and educational experiences; the second focused on program details; and the third was a reflection on the information provided in the first two interviews.

Triangulation, according to Lincoln and Guba (1989), occurs through the substantiation of data by using multiple sources for convergence. Data in this study were substantiated in two ways: (a) through additional interviews during which I revisited data obtained in prior interviews to determine alignment between accounts; and (b) by examining artifacts, or what Erlandson et al. (1993) referred to as referential adequacy materials. An examination of program materials and institutional and program websites substantiated participants' program claims, particularly regarding institutional inclusion. Programs truly integrated into their institutions had websites in which the program was highly visible and included program links as well as links to new articles and other promotional materials. Programs that were more diffused among different stakeholders or were dual credit were more obscure, indicating that those programs were accessed through third parties such as high schools or disability providers. CVs also substantiated participants' descriptions of their work and education, and, notably, the one participant

who did not provide a CV was an individual who had entered the field later in life after taking care of her daughter with a disability; the only credential she held relevant to the field was an associate degree. Lack of a CV or resume supported our discussions regarding ageism in the work force and her feelings of inadequacy.

Peer debriefing allows the researcher to test working hypotheses and look for emerging designs with a professional not associated with the researcher's immediate context, who can ask probing questions, provide alternative explanations, or play devil's advocate (Erlandson et al. 1993). Throughout the research process, I received such peer feedback from committee members, professionals in the field of disability, and other doctoral students, particularly with reference to the divergent case. Lincoln and Guba (1985) suggested that this process should be informal, with a summary kept of its debriefing sessions.

Member checking is continuous. It can be formal or informal, and during this step participants have an opportunity to affirm or disconfirm the researcher's construction of participants' stories (Erlandson et al., 1993). I conducted informal member checks during each interview to confirm that my understanding of those stories aligned with participants' intent and to ask for additional information when I did not understand something. The third interviews began with a summary of the first two interviews, such as the following one with Daphne: "The thing that really stands out in your story of course, is your own disability and that you have lived this life and walked this walk and now you're talking, you know what I mean? Your work seems so informed by your own experiences, which of course no one else can manufacture." To which Daphne replied, "it's true."

A final component supporting trustworthiness is a reflexive journal. Lincoln and Guba (1985) encourage the use of reflexive journals as means for keeping track of developing insights, methodological decisions, and questions prompted along the research path. I alternated between keeping my reflexive journal chronologically or topically, and I also used photographs to capture advances in my conceptualization, posted on a white board or on large sheets of paper. Periodically I reviewed and consolidated my notes and considered them when delving further into the literature, for fine-tuning my focus, for informing interview questions, or for making and justifying methodological decisions.

Keeping a reflexive journal helped to inform my role as a researcher and to understand how my contributions to the dialogues influenced the interviews. I began to consider that my insertion of stories and experiences in the interviews was not merely interruptive, but actually a foundation for co-constructing stories with participants. I began to re-examine my insertions and found that, in most cases, personal additions from my own experiences served to create a knowing bond with participants. It showed them that I really understood what they were saying. I also noticed that frequently, in response to my sharing, the participant added deeper, more enriching stories that supported the topic we were discussing.

Once I realized that my contributions were part of a valuable researcher/participant co-construction of knowledge and not merely interruptive, I understood the importance of my own positionality and the concepts of emic and etic, objectivity and subjectivity. This added yet another level of data analysis, as I learned to



consider the impact that my assumptions might have on my interpretation of participants' stories.

### **Chapter Summary**

This chapter described the research methodology used in the study. Sampling method and participant recruitment were described, and descriptions were provided of the participants, their programs, institutions, and artifacts. Methods for participant safeguarding were also included as was my method of data collection, storage, and analysis. I also included an explanation of my researcher positionality. Finally, issues of trustworthiness which include prolonged exposure, persistent observation, peer debriefing, triangulation, member-checking, and keeping a reflexive journal were described.

## **IV. FINDINGS**

### **Introduction to the Findings**

In this chapter, I present major findings from the study in three sections beginning with themes discovered during cross-case analysis which include (a) administrators' beliefs about the human growth and development potential of students with ID/DD and (b) administrators' knowledge of students' experienced oppressions. Next, I use vignettes to holistically introduce three focus-case studies which serve as exemplars of key findings including; (a) administrator conscientization and (b) administrator praxis. The use of case study was particularly valuable for this because administrators could directly connect their experiences to their work within bounded cases. In the final section, I present a cross-case analysis of all participants considering all four themes introduced in the first two sections; (a) beliefs, (b) knowledge of student oppressions, (c) conscientization, and (d) administrator praxis. This final cross-case analysis of all nine administrators suggests how experiences and beliefs may be connected to praxis, and addresses my research questions:

Overarching RQ: How do the personal, professional, and educational experiences of administrators of PSE programs for students with ID/DD and their beliefs about the human growth and development potential of students with ID/DD impact their work in the field of inclusive PSE?

RQa: What are the personal, professional, and educational experiences of administrators of inclusive PSE programs for students with ID/DD?

RQb: What do administrators believe about the human growth and development potential of students with ID/DD?

RQc: How do those experiences and beliefs impact administrators' work in the field of inclusive PSE?

Participants in the study were administrators of inclusive PSE programs for students with ID/DD located at a variety of higher education institutions in different geographic locations. The institutions represented different types (2-year, 4-year, public, private) with different types of programs (2-year, 4-year) which had different levels of inclusion (amount of time spent by students only with individuals from their own program, availability of on-campus housing, and inclusion in extra-curricular activities). Participants came from a variety of backgrounds and had varying types and levels of personal, professional, and educational experiences with diversity, disability in general, and working with individuals with ID/DD.

### **Administrators' Beliefs**

My post-hoc operationalization of the term *beliefs* was derived from grouping and consolidating data in which the participants indicated some type of knowledge regarding the growth and development of students with ID/DD. Of particular interest were data in which participants connected their students' growth and development with the same process of growth and development that non-ID/DD college students experience. My analysis of these data supported the construction of a definition of administrator beliefs they developed through knowledge gained working with students with ID/DD. The definition of beliefs is; (a) administrators of inclusive PSE programs know through experience that students with ID/DD have the power to grow and develop like all other college students, and (b) administrators of inclusive PSE programs consider students with ID/DD to be just like all other humans and respect their unique differences noting that

individual differences can be supported or hindered by surrounding systems, thus they hold humanizing attitudes towards them rather than biases, stereotypes, or prejudices.

Thus, beliefs are grounded in both knowledge and attitudes. Knowledge comes from witnessing student growth and development in personal, professional, and educational settings, while consideration of humanity and respect for differences is an attitudinal posture linking students with ID/DD to all other humans. Such linkage emphasizes the human-rights foundation of the issue while also focusing on the need for equitable access to and supports in lifelong learning and development for individuals with ID/DD in socially valued places with their peer group.

### **Belief: Knowledge of growth and development**

The participants' narratives illustrated that administrators of inclusive PSE programs develop a knowledge that students with ID/DD have the power to grow and develop like all other college students through their personal, professional, and academic experiences. Maggie, the parent of a medically fragile child with ID/DD described the changes that occurred in her when she was provided with an inclusive, supportive educational experience after spending years in excluding and non-supportive school environments.

Seeing what she was experiencing, being in an inclusive environment and finally getting to do the things she always wanted to do, she blossomed! She became the person that was always there but could never come out because nobody would let her. It just changed her. It changed her happiness; she went from being depressed to being happy, it changed the way that she interacted with people. She went from being an introvert to an extrovert...

Maggie witnessed her daughter's growth and development as the result of being placed in an inclusive and supportive environment. Her personal experience seeing her daughter "blossom" gave her a passion for seeing the same growth in the students in her program. Maggie said, "I see my daughter in every student."

Ethel told a story in which a young man became his own guardian after experiencing growth in her program.

What really sticks out in my mind is we had a student who came in and his mother was his guardian. You know, a big part of our goals is to support students in self direction and self-determination. So, over the course of four years... through these experiences and his internships and learning how to manage his own life, this senior; our seniors have to do a portfolio, which is designed to show what you know, what you've learned, you know, how did this impact your moving forward? What is your plan for moving forward in life? He decided that he wanted to have his rights restored and he went through the legal process – but the way that he communicates makes it difficult to understand, so, he submitted his portfolio as a part of his case, and they used it as evidence of him being able to direct his life and his rights were restored.

Ethel's story demonstrates that students who have both opportunity and support can do the work of becoming more human. They can gain voice and agency over their own lives which in turn gives them increased autonomy and freedom, including, as this case demonstrates, freedom from legal constraints that would limit the student's rights to direct his own life. When afforded such freedom, Ethel stated;

the student blows out their own expectations for themselves and the folks around them. That's a beautiful thing, you know, no matter who you are, that's a beautiful thing. Especially for students who have not experienced the freedom.

Emilia stated that her favorite thing was watching students grow:

My favorite things I'd say, is to see them grow in many different ways, they can grow, academically, they can grow socially, they grow in their curiosity, and in their independent living skills and so on. To me that is the most important thing and now that I am working with young adults here—it's been fascinating to see that they grow, you know from the beginning of the semester to the end of the semester in a totally inclusive way where they're living independently and people are saying "Oh wow. That's a big feat!" and I'm like, it is, but they're doing it and they're having fun.

When I asked Emilia about her role in student growth, she stated, "I just provide the space for it, but the power is in the student." Emilia emphasized that the growth potential is in the student already, and that providing the opportunity to exercise growth is where her administrative role becomes important. She noted that students grow in many ways and said that she can see the difference over time from the beginning of the semester to the end of the semester.

Emilia and Daphne both talked about student individuality. Daphne attributed growth to adequate support and "the right hook," stating that "I think that everybody, if you can find the right hook, almost anybody, you can motivate them to get moving in the direction that allows them to excel."

Emelia put it this way; “we have to look at students as a whole, they’re not just a score; the same way that I think we’ve been boxing in the rest of our traditional students” and referred to “how to get people to buy in and just see the students, the individuals with disabilities for who they are rather than their disability.” Daphne emphasized the importance of understanding differences which influences practitioner approach:

It was a passion of mine to assist persons with new conditions to figure out who they were as a person with a disability and to recognize that there were a lot of talent and skills that they still had.

### **Beliefs: Consideration of Humanity**

Lori said succinctly that “people with ID/DD are just another permutation of us,” and Rachelle said that the most important thing people need to know when working with individuals with ID/DD is that “every person is just a person.” Jane stated, “This is a person with a disability, not just a disability” and elaborated on her beliefs;

My core beliefs about disability or people with disabilities is that they’re people first. That’s how I look at the world in general. Everybody at some point is part of a group or not part of a group. I’m a female, not a male. I’m an American, not a European. And I don’t know if it’s because I started working with people with disabilities when I was so young that I have no division between people with disabilities and people without disabilities, but I think they have the right to work, the right to not work, the right to get married, the right not to get married, the same human and civil rights as every other person on the planet. I think, as far as core beliefs, it just sort of ties into how I am as a person with all of humanity.

Jane made the distinction that being part of a group does not diminish one's humanity, and Bobbie also had much to say about person-first language. She recognized that in some disability circles, individuals want to have a label, such as "I'm an autistic person," but she explained that she did not want the students in the disability classes she teaches to do that. Bobbie cautions her students against thinking that the system can turn people with ID/DD into products and does not allow them the opportunity for self-expression. Bobbie said; "So, I'm wondering if what's missing in a lot of special education programs is any kind of way to emphasize that the students are people."

Bobbie continued;

I don't know if you have seen some of the news on person-first language lately...I really try to stress with my students who are kind of new to the field, like, I want you to go person first unless corrected ... I need you to think of the person first...I need you to change your thought process...I think that's something to really, you know, kind of be considering, that they are people.

Bobbie realized that she had to change her students' mindsets from the beginning, to consider that they are talking about people and not just a disability. Even if those with disabilities begin to address themselves using their disabilities, Bobbie felt strongly that others should not do so, because it can obscure the fact of being a person as opposed to being a disability. Bobbie explained the importance of this by pointing out that we can make laws that say, "an autistic person can't 'whatever,' and intellectually disabled people can't 'whatever,' but we can't make a law that says all people can't, right?" She also pointed out that disability groups are large, and that "anyone can join at any point."



Here, Bobbie is referring to the point that we all may experience disability at some point in our life whether temporarily through illness or an accident, or degenerately as we age.

Bobbie connected these thoughts to what she witnessed happening with the students in her program. If a student in her program fell asleep in class, or forgot to raise their hand before speaking, the staff made a huge deal of it, attributing it to the disability and inability to comply, but Bobbie considered that these are normal college student behaviors up to a point, arguing that, in order to develop, students must make those mistakes and then grow as they reap the consequences and learn from their experiences. She said, “I started having to say, hey, come on people, like pull it back.” She wanted students to have the room to be like other students and not always have 100% controlled behaviors which can be the outcome of intensive behavior therapy rather and doesn’t indicate education in which students learn to make their own choices and develop an internal locus of control.

Javier talked about the evolution of his ethics and values related to students with ID/DD. One of his earliest jobs consisted of driving a bus for people with ID/DD, and during this time, he experienced a critical incident that made a lasting impression, which, as he said, “cemented” his work in the field. It demonstrated his belief that people with ID/DD are people and not animals and should be treated with dignity and respect. He described this incident in our first interview.

Out came two supervisors, and each had a woman’s foot and they were dragging her out of the door and to my bus. And they just kind of dropped her feet on the first step of my bus and then left and she had this dress on, it was this sort of gray and blue patterned dress, but it was a dress, and it was pulled up over her head.

You know, I was 23, 24 years old and I was shocked. You know, I took off my spring coat and folded it up and put it under her head. Her name was Melissa, and I said; “maybe we should just wait here for a little while, ’cause I don’t know what just happened here, but I’m thinking those boys owe you an apology.

Javier then went to find the workers who did this; when he did, he said to them,

Gosh, I don’t know what went on here, but I know that I have people on my bus, not cattle, so if you could come out and help Melissa up, dust her off, and apologize, I’d be on my way.

Thus, Javier made a specific distinction between humans and animals, as he described how the experience prompted two thoughts that have guided his practices ever since:

And the two questions are, (1) how is it that good people can do harmful things in the name of good? And (2) what can I do about it? And those two questions cemented my work with people with intellectual disability.

Javier may or may not have been in tune with his beliefs and values before this incident, but, seeing the abuse and neglect of a vulnerable individual certainly prompted him to clarify what he was witnessing and determine what his role would be to counteract what he deemed to be inhuman treatment. Because Javier was so in tune with his beliefs and values and because we had also talked about his Catholic school upbringing, during our third interview I asked him directly about his beliefs: “What are your deep held beliefs about people with intellectual disability?” Javier gave a rather long but complete answer.

[silence] hmm. I don’t mean to be cliché, but, maybe it speaks to my, you know, in a lot of areas, I’m not very smart, and one of those areas is that I can’t figure out the exact difference between people who are classified as having intellectual

disability and people who aren't. Now, I don't mean to seem silly, I can see the difference in behaviors. and I can see differences in how I have to communicate. I mean I can see differences in their experiences that have brought to them a culture of expression, that, you know what they do how they it and how they say it and so forth and so on, so I don't mean that. And I don't mean to be sort of surface in that one might think "Oh, a person, anybody can do anything" no, because I understand THAT...[emphasis Javier], because I can't be a lawyer. I always wanted to be a lawyer, but I'm just not smart enough, so I don't mean any of that. But I do mean, that my fundamental belief is, and it is a belief, is that when I meet someone, my ability to understand who they are is my ability and not their disability.

In his comments, Javier pointed out that overcoming differences among individuals involves shifting approaches rather than labelling deficits and that problems regarding the ability to understand another person should inspire educators to problem solve rather than assume a lack of intelligence or inability to communicate.

Thus, all nine administrators stated in some way that they believed students with ID/DD could grow and develop because they had personal knowledge witnessing such growth and development. They also made clear statements placing individuals with ID/DD on a continuum or spectrum of human variation rather than having significant or fundamental differences indicating a less-than-human status and noted that, like other humans, education focusing on their strengths and with proper supports, was the most effective. Although the administrators pointed out that different approaches in support and instruction created specifically to provide better results for students with ID/DD

might also be valuable for individuals not diagnosed with ID/DD. Javier summarized it well when he put the onus for adapting supports and behaviors on ourselves, rather than placing blame for difficulties on others because they are different from us.

All of the administrators indicated that they saw individuals with ID/DD as people first and that any designation such as *intellectual* or *developmental disability* was inconsequential to their belief in a person's basic humanity. Altogether, the administrators' experiences provided the basis for the emergent definition of beliefs in this study: (a) administrators of inclusive PSE programs know through experience that students with ID/DD have the power to grow and develop as do all other college students, and (b) administrators of inclusive PSE programs also administrators of inclusive PSE programs consider students with ID/DD to be just like all other humans and respect their unique differences noting that individual differences can be supported or hindered by surrounding systems.

### **Administrators' Knowledge of Student Oppressions**

The administrators all shared a belief in the ability of students with ID/DD to grow and develop over time and emphasized that education targeting strengths rather than weaknesses is certainly a key to promoting such growth and development. In this section I turn to the administrators' knowledge of situations that limit, or oppress, this growth and development. As Freire said, oppressive practices are dehumanizing. One of the central tasks of critical research is to identify sources of oppression for marginalized and disenfranchised people so that they can be mitigated through policies and practices. All nine participants referred to circumstances and practices that limit the growth and development of students with ID/DD that are part of the students' environment and do

not emanate from their disability. In this report, I refer to these environmental oppressions as *external* oppressions. External oppressions, however, can become internalized by individuals with disabilities which can lead to the development of self-limiting attitudes based on prior experiences that further limit the individual's growth and development (David, 2014).

### **External Oppressions**

In the following section, I report the types of external oppressions that administrators talked about during their interviews. These include negative attitudes such as bias and prejudice, false generosity or pity/charity, lowered standards and lack of opportunities, parents, and institutional barriers. Each contributes in a unique way to student oppression, some overlap a bit, and, in some cases, an oppressive source can also be the source of liberation, such as parental attitudes.

### **Bias and Prejudice**

External oppressions include attitudes that people may have toward individuals with ID/DD, such as biases, prejudices, and pity. These attitudes can contribute to bullying, exclusion, and assumed incompetence, which in turn contribute to educational practices such as lower expectations and limited opportunities. Some of these practices result in students' being behind in basic age-appropriate skills such as decision making, whereas others become internalized, making it hard for students to differentiate between what they've been told or how they've been treated, and who they really are and what they want out of life.

Bias and prejudice are forms of external oppression that create barriers to growth and development opportunities for students with ID/DD. Bias and prejudice consist of

attitudes and behaviors directed toward a group that are based on unmerited judgements. Javier, who frequently mentioned such attitudes, spoke of their negative impacts on the students and on their relevance in the establishment of his program. In the conversations on campus during the program's planning phase, Javier noted that "there were just all these questions. Some of them were sort of mythological worries based upon bias and prejudice, but, nonetheless, they were questions being asked by the gate keepers." False assumptions (bias and prejudice) were thus linked with actions (the gatekeepers had the power to say yes or no to establishing a program), which in turn led to policies (the university did set up a program, which created the need to establish new campus policies to include students with ID/DD). After the program was established, Javier noted a shift in these ideas.

I really don't know how this happened. It's like the university has had a love affair with our program, and not from a pity/charity perspective. This isn't about puppy dogs and children that make us go "aww." It was a little of that to start out with....but, you know, many of the learned people who operate on a higher level are thankful for an example of what inclusion looks like and not just diversity...it reminds them why they got into education to begin with. That is; good public education for the public good, and those things spill out onto us."

Javier's story demonstrates that before people are acquainted with students with ID/DD, they may bear certain biases, prejudices, or other unmerited assumptions that can be changed once they have the opportunity to interact with the objects of their uninformed biases. The campus police, for example, assumed that students with conduct issues were his students. When the police found out that they weren't, they were forced to

reconsider their assumptions, and when they began to pay attention to what the program was doing to keep its students safe, they realized that “gee, those are great ideas, we should do them for everybody.”

Daphne noted that biases were one of the barriers to inclusion at her campus: “individual faculty or staff bias in regard to wholeness as a person. You know, again, I’m just paraphrasing; that a person who has special needs and so we need to treat them as such.” Jane tied biases to ignorance about the benefits of the programs: “they’re [the students with ID/DD] going to college where a lot of people don’t understand the outcome of a program like this. I mean, it’s just sort of like any other bias or discrimination, coming from a place of ignorance.”

When I asked Emilia what the hardest thing about working with students with ID/DD was, she brought up the unconscious biases and assumptions of others:

I would say other people. I would say the most difficult things are the barriers put in place by society as well the structural barriers. For example, here at the university. Thankfully we’re able to get through many of them, but I think that many people within society view them as “they cannot do things” so “they cannot grow” and to me that’s the most difficult thing. How to educate people and how to get people to buy in. and just see the students, the individuals with disabilities for who they are rather than their disability.

Emilia noted that biases and assumptions prevented others from giving students with ID/DD a chance to grow and develop. Ethel considered “attitudes” to be barriers, and Lori responded to the same question with a litany of damaging assumptions, which she classified as stereotypes.

Stereotypes! and It's the stereotypes that the person with a disability holds. The stereotypes that the institution propagates. It's the stereotypes that grown-ups who are hard pressed to step out of their little box, maintain. When you can bust those up, then you make progress. And all those stereotypes look different, you know, so it might be the university, or the organization presents barriers, process barriers. The person with a disability has a lack of self-confidence. A person without a disability who's looking at the other adults are afraid that they might get it wrong. Yeah, so there are all kinds of the reasons that the stereotypes exist. There's all kinds of underlying issues and you have to figure out where they're coming from and how you're gonna approach dismantling those stereotypes.

Each administrator noted that some type of assumption, bias, stereotype, or negative attitude played some damaging role in their students' progress. Javier noted that prolonged exposure to students with ID/DD can help alleviate those biases. One aspect of Lori's response stands out in contrast to all the others. In listing stereotypes, Lori included students' stereotypes about themselves. This a key finding, which I will revisit in the section on internal oppression and in the key findings at the end of the chapter.

### **False Generosity/Pity/Charity**

False generosity, pity, and charity as approaches to ID/DD are oppressive practices, because they perpetuate the idea that individuals with ID/DD are different from everyone else and cannot do things for themselves. Jane recalled the first time she became aware that people pitied students with disabilities.

I was in that class listening to my classmates in college refer to people with disability almost in like a derogatory way, and that they should be pitied and that



they're treated so differently. That's when I sort of became aware that there was a difference in people's treatment of them as though they weren't part of our population, that they weren't part of our group. That we need to pity them, and that we're good people because we want to care for them. That was the first time it really hit me. I remember thinking these people really should go into this.

Later in her interviews, Jane noted that:

Society perpetuates the idea that people with disabilities are to be pitied. That's probably what drives me the most crazy; and because it's a discrimination that does not come from hate, but comes from pity, it is very hard to fight because people think you're a horrible person.

Jane also noted that considering individuals with ID/DD as deserving pity rather than as a part of one's group is not just derogatory; it is a difficult attitude to fight because it doesn't come from hate, and to fight pity can subject one to moral criticism.

Ethel also considered pity to be a barrier to inclusion. She specifically noted that the "world of accommodations," which requires proof as a means for eligibility, forces students into a beggarly stance:

It's pushed me to trouble this idea of inclusion, of what inclusion really means. You know, we say person first language, and we say that we're moving past the medical model [of disability], but when you look at the world of accommodations, particularly at the university level, it's still steeped, it's so anchored in the medical model. It's so frustrating to me to see students, whoever they be, whether they're students I'm working with or not, have to go in and prove, **and prove** [she

repeated in an escalated tone] that they have the prerequisite deficits to be able to be eligible for support. It just absolutely makes me crazy.

You know, rather, can we look at our pedagogical practice? Can we look at universal design, can we move past universal design into some more engaged practices where we are teaching everyone, so that you don't have to go in with your and out, with your hat out? No, No! I deserve to have support! What is that about, right?!

Ethel's comments demonstrate that the way our systems are set up, we put students into subjugated positions, setting them up as students who are "less than" and requiring them to ask for service, rather than creating environments that meet students' needs through universal design and engaging student practices. Ethel's comments echo those of Noddings (2015), who argues that education should support the unified goal of producing better adults, and not serve as rigid academic disciplines that help to sort students into varying levels of abilities.

Emilia pointed out that instructors must consider their own approach to educating students with ID/DD: "especially when you're talking about that pity model, because it takes an extra step on being reflective of, what does this word mean and what does it mean to be a special education teacher?" Pity is a stance that comes from feeling sorrow or compassion for others based on a perception that they are suffering or misfortunate. A stance of pity assumes that individuals with ID/DD are experiencing life with some type of deficit that should be judged a misfortune. Emilia, however, reminded that educators need to reflect and ask themselves "why we're doing the work that we're doing."

## **Lowered Standards and Lack of Opportunities**

Every participant referred to external limitations imposed on students. These included limitations caused by lower social and academic opportunities, lack of opportunities to explore the world and practice making choices, and exclusion.

Daphne, with firsthand experience in the special education classroom, noted that students in special education received a “dumbed down” curriculum:

There was a lot of rote action. It almost felt like babysitting and not about education many times. It’s kind of sad because there was a lot of good and talent in the room that could have been harnessed and nurtured.

Maggie lamented that special education frequently takes place in isolating and segregated locations:

It’s always been, they’ve always been segregated. You know, a lot of, a lot of, um, students with intellectual disabilities and special education programs. And my daughter was one of them. They sometimes were in mainstream classes, but a lot of times they were in their, their own classroom and that classroom was down the hall, you know, down, a few steps in the basement, back some dark hallway where they didn’t really interact with other students. And if they went to a mainstream class, the other students would be like, who’ that? You know? And, and it’s been like that for so long and so it’s just always been so exclusionary and that’s kind of what students like that expects a lot sometimes.

Maggie pointed out that special education students are frequently relegated to inferior, separate spaces in schools. She also made a connection between students having these inferior and excluded experiences and then coming to expect, rather than question,

them. Javier described the impact that exclusion had on some of his college students when they were told they didn't need to complete an assignment that all the other students did as a requirement for a 3-credit music dance course. Javier said that being excused from the project

had a visible negative effect on the students. Behavior wise, they immediately accepted their lot and they went and sat, slouched shoulders, over in the corner, waiting to be called back to belonging, something they probably had become accustomed to ...someone who thought they were doing good, by saying 'gosh I don't know if they can do this, so they don't have to. Javier's example connects both the negative impact of exclusion with the danger of separating students with ID/DD from others and dismissing them from having the opportunity to try.

Jane pointed out that "there's always an exception made for students that are in special education...even with inclusion, there's no expectation that the person who is with a bunch of 14-year-olds will take home the assignment and bring it back the next day." She also pointed out the inane "work" that is sometimes given to individuals with ID/DD, something Javier talked about too. Jane described a sheltered workshop where she was once employed:

In the sheltered workshop they would do things like have a line of people sitting at the table. The first person would open a Ziploc bag, the next person would put in the fork, and the next person would put in a spoon, and the next person would put in the knife, and the next person would seal the Ziploc bag. And then there was an employee of the center who would dump it all out. And then they would do it again, all day long. And it made zero sense to me...and I was new to the

plant, basically getting into trouble because I kept talking to everybody in the sheltered workshop like; “How do you feel about putting a fork in there and then somebody else takes it out?” and they’d go “it’s really stupid” and my boss was like “you’re disrupting them, don’t do that.”

In addition to pointing out a limiting work opportunity, Jane introduced her questioning approach to the individuals with ID/DD she was working with, prompting them to question their experiences as well, rather than just accepting the status quo. These examples of lowered expectations and exclusionary experiences demonstrate how pervasive and complex they are, particularly when the actual practice is generally preceded by a bias or assumption and the result is internalized by the student either as something they should expect, as an edict on their capabilities, or even worse, possibly something they deserve.

### **Parents as Barriers**

Nearly every administrator reported that parents could be both the best supporters and major hindrances. Most of the administrators recognized the difficulties that parents with children with ID/DD faced in raising their vulnerable children; however, they clearly recognized that the actions of parents, particularly relating to overprotection and controlling behaviors, created barriers to inclusion for students with ID/DD.

Javier noted that for many students with ID/DD, when they move to campus, it’s the first time they’ve ever spent the night away from their parents; and most of the other administrators stated that retention problems are almost always the result of parents’ guiding the decision to come to college rather than students’ wanting to be there and making the choice themselves. Emilia said that one student “didn’t want to be here in the

first place, he was in a way pushed, or pressured by his parents.” Jane noted that all the students who had left her program left for the same reason. She said, “it is a different perspective about what they’re able to do versus what their parents thought they’re able to do. And when the parents don’t agree with us, it rips the student apart, which is why I’ve really adapted to the way that we communicate with the families.”

Bobbie described a student who was impacted in her dual-credit program. The student had learned to navigate her way around the campus and get to her classes all by herself, but when her mother found out, she completely panicked and said that “she does not want her out of anyone’s sight at any given moment of any day...She now has to have somebody watching her and can’t even go into the elevator alone, and our buildings are super small.” Bobbie said that “the student is pissed, like, rightfully so.”

Jane told a story that happened early in her program’s development, about parents who had trouble relinquishing control when their child went to college. They barraged Jane with emails stating what they thought should be done in the program. “I remember them saying that they didn’t want him to drink coke, and I remember telling them, coke is a legal substance and it’s available in the cafeteria, and he’s 21.” As she reflected, “I don’t think it’s uncommon for parents to feel like they have more of a voice in their child’s education because they have to be part of the IEP (individual education plan) process K–12.”

Given that students with ID/DD are extremely vulnerable and, given their diagnosis, may lack self-direction, it is not surprising that parents might develop a tendency to overprotect. All the administrators understood this and sympathized with parents, but they also set boundaries around parental interference where possible, which

included limiting contact with parents and having parents sign contracts stating that they understood that expectations at the college level are quite different from those in K–12.

### **Institutional Barriers**

Eight of the nine participants brought up institutional barriers. Rachelle was the only one who did not discuss specific institutional barriers, because her program was over 30 years old. It constitutes its own department on campus, with an alumni center to support students when they exit the program. The other eight participants, however, all mentioned institutional barriers that had to be navigated in order to proceed and implement their programs. Institutional barriers included attitudes, as well as systems that needed to change in order to incorporate students with ID/DD (i.e., matriculation status and student coding, housing and dining packages). Barriers also included academic standards and course prerequisites.

Daphne pointed out that “many colleges have admissions standards and things of that nature which often keep individuals with ID/DD from being able to attend.” She also mentioned barriers such as course prerequisites and general education courses that must be taken before a student could take a course that might be more engaging for them. Emilia brought up barriers such as standardized tests and IQ scores, which focus on students’ deficits rather than strengths and do not consider the ability of humans to grow and change or that this ability is not fixed. Emilia said, “We talk about deficiencies in adaptive skills you know, thinking about IQ scores and things like that. I see that I’ve been shifting my mindset and am trying to help people shift their mind set into a more strengths-based perspective.”

Matriculation status was a barrier for most institutions, but once the institutions provide a student code, students are entered into online systems that give them access to all other systems available to other matriculated students. Ethel mentioned that “the students are coded, pretty much like any other matriculating student here,” linking them with financial aid, housing, and all other campus services. Javier recalled that during prior attempts to start their program, not having a code was a barrier. “When we thought about starting a program, we had a collaboration with a local high school where students in transition would use our campus for social events, movies, sports, and so forth, and when we tried to have them get jobs on campus, there was a big barrier because they weren’t officially students...and what about liability?” Eventually, Javier said that resolving the admit code was “rather easy.” They used a code that was already in existence for part-time non-degree students, which allowed the ID/DD students to become “regular students.”

The administrators also discussed the need to gain buy-in from institutional gatekeepers. Emelia said that her program gained traction when it got funding “as well as buy-in from the university.” Rachelle, Daphne, and Ethel all used the word “champion” to describe the buy-in they gained from people in power on their campuses. Although her program was already established, Rachelle supported these statements, suggesting that programs could use “guidance for how to find champions on campus and how to appeal to people’s interests in social justice and access.” Daphne mentioned that someone on the board at her institution was “a huge champion, and he’s in a powerful position to be a huge champion.” Ethel said, “the associate provost, she is a champion for our program, a very staunch supporter.”



Emilia mentioned getting through many of the structural barriers on campuses, and Ethel detailed their struggle to get space before they became integrated into the campus. She described their early years:

We had to find space all over campus. It was, like, commando! I can tell you so many places across this campus. We found them to have class. Because we did meet some resistance early on from the administration who were just really concerned about the safety of students with ID/DD. We were meeting some walls and some barriers, but we didn't stop...it took four years to finally get to a place where our students were categorized as University students.

One surprise place that proved to be a barrier for many of the programs was the ODS office. Daphne's program emanated from the ODS office where she worked, but others described ODS as an unexpected barrier. ODS offices were described as not wanting to work with students in the programs and going so far as to refer to them as "participants" rather than students even if the official college designation was "student." Other participants also noted that when ODS and other health and counseling services don't want to work with "those students," they create further differentiations between students with ID/DD and other students, emphasizing differences rather than building on commonalities. Jane described her experience thus:

When we first started our program, ODS was very resistant to working with us. They would not call our students "students," they called them participants, and they refused to provide services for "participants auditing programs." But the white paper that really regulates disability services says these students cannot be

denied services there, so it was a little bit of a battle when we started, but we're good now, and I've actually heard that's pretty common.

Regarding ODS, Javier was quick to point out that not serving the students in the program would be a violation of federal law, but that they would not be required to provide any type of accommodation or support that they did not provide for any other matriculated college student. Bobbie pointed out that students in the dual-credit program, who were still in high school, received services parallel with those that ODS provided, but that she didn't want students coming to campus in connection with disability alone. "I kinda like it," she said.

We are an inclusive program for students with ID/DD, but if we went through ODS, then it's just automatically disability. Since we stand alone, we're kind of like a trio or an urban ed., so it's just another population coming to campus.

Bobbie did say that if the students were college students and not dual credit, she would definitely have them go through the ODS office for accommodations and services.

Most of the administrators mentioned that when things began coming together to implement their programs, it seemed almost providential; or, as Emilia said, "serendipitous...all the pieces aligned." Daphne said, "I have to say that there must be something bigger helping to orchestrate all the right players and ideas and monies and people and whatever to coming into the right places and positions at the right time," and Javier mentioned a series of events that all lined up during a one-week time frame. Earlier in the week, he was having lunch in the dining room with a colleague who was also interested in inclusive PSE because he had a son with a disability, and the college

president came over and asked to join them. The college president had had prior experience with another program and had been on the board of a disability organization. After the lunch, Javier realized “I had a friend in the president.” He then continued his story: “That very same week that we sat down and had lunch, one of the grant receivers backed out [from an inclusive PSE start-up grant] and they called me in a panic and begged me to take \$50,000!” “The same week the \$50,000 became available, the president said what he said, and so the two together, things just lined up!”

In summary, barriers exist in all forms, from biases and prejudices to systems such as admissions and matriculation, finding space, and working with disability service offices. But all the administrators demonstrated tenacity in getting around barriers one way or another. Daphne described forming a group to apply for her program’s initial grant and focusing on getting “all the barriers out on the table to see ways we might break down some of those barriers, overcome some of those barriers, go around some of those barriers”; and Jane commented, “Sometimes I wonder if the advocacy is ever going to stop in my life time,” but noted that after getting around initial barriers, her program became “pretty much part of the fabric of the university so that everybody has an idea that we’re here, they’re not quite sure what we do, but we’re thankfully out of that place of needing to fight for our existence.”

### **Internal Oppressions**

In addition to talking about external oppressions (barriers) that limit student’s inclusion in educational practices, all of the administrators referred to the impact of internal oppressions on students. As Maggie noted in her comments about being relegated to non-inclusive pedagogical spaces, students become accustomed to external oppressions

and don't question it. Daphne pointed out that "individuals with limited experiences and limited life experiences and the opportunity to have life experiences really need our patience and understanding and maybe the ability to explore above and beyond what may be the traditional amount of time." She also noted that they had to "figure out who they were as a person with a disability and to recognize that there was a lot of talent and skills and that they still had despite whatever barriers they were currently experiencing."

Daphne understood that when students with ID/DD arrive on campus they are sometimes immobilized when finally confronted with choices: "they're either self-limiting or they're utterly overwhelmed and confused and regress back to the desire to be in that sheltered, structured environment they are very much used to and which is comfortable." In this statement, Daphne was referring to the way that students with ID/DD internalize all the oppressions they have experienced. She used this knowledge to make decisions about program supports, but she did not blame the students for having such feelings.

Javier remarked on his observation that when students with ID/DD enter a PSE program, it might possibly be the first time they have ever spent the night away from home:

In terms of the identity that delivers you, that has to be profound, and entirely extraordinarily awesome. Starting small with "I get to decide what I eat" and "when I go to sleep, and when I walk outside and when I don't" and expanding to "I get to choose my courses and my friends" to "I get to choose a job, and gosh, maybe have a little agency in my own life."

Of course, other college students might not have to establish identity at such a basic level. As Javier pointed out, students with ID/DD may experience things for the first time that others simply take for granted, and this can greatly impact their development.

Ethel too linked freedom from limitations, growth and development, identity development, and similarity to other college students:

When they finally come to college and they have this identity as a college student, and then they see college students doing all of these things that opens up possibilities for them...and then they tap into capabilities that they might not have even known they had...so I'm passionate about that the potential of college education because of that discovery piece, it's the hugest thing. They come here and they have no idea they can do it. I mean, this is true for any college student, right? ...you know, the growth process. But I think for our students, because they have been so limited before, they get here, and the growth we see is huge and I believe that being exposed to possibilities is a big part of that.

Rachelle also made comments regarding this additional shift that students with ID/DD need to make as they learn a new identity as a college student, moving past labels that may have been attributed to them for their entire lives up to PSE.

That's the thing that means the most to me as a professional, seeing someone who defines themselves strictly as a label and a disability, and to see that shift into 'I am a capable human being. I have strengths like all people, and I have weaknesses I can fill with support. And I know that I am worthy and capable of living this life.' That's the most important thing to me, but I think it's the hardest thing to pull data for.

As mentioned previously, the administrators' narratives included stories about parental control and imposition of the parent's will on the student. In such ways, parents narrate students' own stories *for* them. Ethel expanded this to include not giving students enough time to speak for themselves. She pointed out that when we ask students questions and are satisfied with simple responses, we encourage them to develop a superficial personal narrative rather than encourage them to "dig deeper." Bobbie, who has a background in behavioral therapy, explained how this controlling narrative is entrenched through both behavioral therapies and special education practices that constantly police and control student behavior. Such external policing does not allow for internal student growth, which naturally occurs through trial and error and experiences of failure.

According to Bobbie, behavior therapy is a form of strictly controlling behaviors that can frequently keep students from growing and developing through normal trial and error. Behavior therapy can also encourage rigid behaviors that are non-adaptable to changes in context. She provided the example of a student reaching their hands down to touch their genitals. In an elementary context, the student might be instructed "good hands, you know we don't touch ourselves there." But Bobbie pointed out that people, particularly boys, do "adjust themselves": "We don't put an age on it or teach appropriate times, like they shouldn't be swearing at their teacher or trying to masturbate in class, but we don't give them room for error. I feel like we're trying to make perfect citizens because of those expectations we create for them." She also pointed out that "we have this idea of what an ideal college student should look like and that's how their staff are kind of guiding them to look like instead of looking like other [real] college students."

She said, “the scripting I see at this age, I can tell which students went through really intensive training as kids, especially for conversation skills...we don’t train them for generalizations either.” Bobbie mentioned the paradox of students in special education who have one-on-one supports, explaining that the effort to get students to be 100% compliant means that they don’t have the chance to develop their own thinking. If a student drops a pencil, the student doesn’t have time to stop and think about picking it up because the support person immediately says, “pick up the pencil.”

Daphne talked about another kind of scripting that takes place when we avoid hurting someone’s feelings.

You know, nobody ever looks at you the wrong way, or are challenged in a way where they might feel bad about themselves. I’m sure it’s with all the best intentions, but with adversity comes triumph and learning. I think we often take those aspects and pieces out of an individual with disability’s lives because we don’t want to crush them, or we don’t think they can handle it, or whatever the case may be...we tend to script all of these things out so that the individual doesn’t have a chance to. They need to pick out their own stuff, dream their own stuff, and be challenged in a way that might help them to grow.

Daphne pointed out that overprotection prevents students from growing properly.

Students with disabilities need to recognize themselves as students with disabilities and understand all the ramifications of that identity even if it is not always positive or pleasant. Ethel mentioned the same thing when discussing her own identity development.

When she was a child, her white mother approached Ethel’s mixed race with a love-

conquers-all approach, but Ethel reflected that, years later, her mother wished she had approached it differently, because

the reality of life in this country is that you're going to be judged...it's going to be a part of how people see you, so you need to be aware of that. It shouldn't limit you, but you should be aware of it.

In summary, all the administrators recognized that students with ID/DD may have internalized external oppressions that they experienced before coming to campus. As a result, their growth and development once they arrive at campus may be significantly different from that of typical college students. Failure to recognize this atypical growth might result in a failure to provide appropriate supports. Dumbed down curricula, social and academic exclusion, limited exposure to opportunities, bullying and exposure to biases and prejudices, parental overprotection, and overcontrolling behavior all serve to teach students with ID/DD the boundaries of their existence, whereas college can free them from such limiting self-beliefs.

### **Summary of Themes**

The administrators of inclusive PSE for students with ID/DD in this study all held similar beliefs regarding the potential for growth and development in students with ID/DD. Each indicated this belief either by stating it directly or by describing a scenario in which a student developed over time during their program. Each administrator also indicated that students with ID/DD could be compared to any other person or student and that by providing students with ID/DD with the same opportunities as those for everyone else, they can grow, like everyone else, particularly when opportunities focus on their strengths and not their weaknesses. Finally, regarding beliefs, the administrators



indicated that the growth happens because of something inside the student and is not merely a result of an external factor, although external factors can promote this internal change.

The administrators of inclusive PSE for students with ID/DD in this study also had knowledge of the many ways that students with ID/DD have been oppressed by external circumstances. These oppressions include limited opportunities to learn and grow and to experience activities which open up future possibilities for them. The administrators also acknowledged that students may internalize these oppressions as well, and that they may limit themselves in accordance with the prior limitations imposed upon them. Additionally, some of these self-induced limitations may appear to be behavioral or motivational issues, but stem from reactions to prior experiences rather than from personal characteristics or tendencies.

In the first part of this chapter, I presented the major findings of my naturalistic inquiry into the personal, professional, and educational experiences and the beliefs of administrators of inclusive PSEs. In the first section, I introduced the two themes that were collaboratively assembled across all nine participants: (a) beliefs—contributions to a collective definition of beliefs which includes knowledge regarding the growth and development of students with ID/DD and attitudes concerning their placement on the spectrum of human variation, and (b) student oppressions—contributions to a collective understanding of oppressive situations that can impact the growth and development of students with ID/DD. These themes provide a foundation understanding the focus of the following sections on individual experiences and practices, first with three focus cases and then with a cross-case analysis.

### **Focus Cases: Daphne, Ethel, and Lori**

In this second section, I provide vignettes from three exemplary cases: Daphne, Ethel, and Lori. Vignettes offer a short, holistic overview that can reveal an issue's complexity (Stake, 2010), and these three vignettes will help to introduce the interwoven nature of the administrators' personal, professional, and educational experiences. I start with Daphne, whose personal experiences as a woman with a congenital disability guided most of her professional and educational experiences. Next, I present Ethel, whose personal experiences with diversity and her exposure to inequities faced by individuals with ID/DD were her impetus for seeking education that addressed social justice and identity issues. Last, I present Lori, who had no proximity to disability or diversity, and who simply found personal joy and satisfaction in working with individuals with ID/DD and pursued education through the doctoral level in special education to enter a career in the field. Following the vignettes, I will deconstruct their stories into three categories; beliefs, conscientization, and praxis, which sets the stage for my discussion in Chapter V.

#### **Daphne: My Life is Basically That**

The words that came out of the doctor's mouth sent Daphne's mother into a panic. In 1976, the year Daphne was born, a diagnosis of cerebral palsy left much uncertainty, and Daphne's mother, along with the doctor, wondered "Will she die?" "Will she be able to talk?" "Will she ever walk?"

Her mother quickly set to work to "figure out what we need to do," and as a toddler, Daphne was enrolled in an early childhood training and therapy center run by United Cerebral Palsy. At the center, she received expert care and education, which included assistance with mobility issues and functional and academic skills. She learned

to navigate in a wheelchair. When she transitioned to public elementary school, even though she did not have a cognitive disability, she was placed predominantly in special education classes as well as a few mainstreamed classes, and she participated in Special Olympics. Reflecting on these experiences, Daphne recalled that she always recognized that there was a difference between her abilities and the abilities of the rest of the children in special education. She recalled assisting the other students in the special education classes.

At that point in time, I viewed it like, you know, you're a kid and you get some sense of authority and power. And, it's probably negative, honestly, it's not a good thing, as I'm talking about it out loud with you now. You know, I had authority and power. Here's something I can do, and it feels pretty neat to demonstrate or show or provide this answer to other kids...I would say that in some respects it was good because I had that early understanding and interaction and ability to kind of see what they were required to do and how they were treated and didn't always get the best support that they should have, and oftentimes dumbed down kind of stuff rather than going towards their ability. Unfortunately, on the other hand, not having the training and understanding I now have and that you want to empower the individual, you want to know what they need to do to help themselves, that kind of mind set probably was not the best.

By sixth grade, Daphne's mother realized that she wasn't being challenged enough, and requested that she be mainstreamed with the other students. Once mainstreamed, Daphne preferred to utilize natural supports to get the assistance she

needed for most day-to-day school-related tasks, and she relied on formal supports to use the restroom or if she needed a scribe for a test.

I could go get that person when I needed it, but I didn't want that all the time. I wanted to be my own person and utilize natural supports before I knew what that meant. "Hey Johnny, can you help me pull the book out of my book bag? Can I get a copy of those notes?"

Daphne went on to earn a bachelor of science degree in rehabilitation services and a master's degree in counselor education with an emphasis on rehabilitation counseling, but her plans to be a rehabilitation counselor were interrupted when regulations shifted to require counselors to have a PhD, and so she was constrained by finances to seek employment instead of continuing her studies. Daphne has experience as a practicing therapist and as a disability learning specialist and assistive technology coordinator at several institutions of higher education. She has served at her current institution for over 13 years, and she was recently promoted to full professor and disability learning specialist.

Daphne's personal experiences are deeply entwined with her experiences of education and work. When I asked her about her work, Daphne said "I haven't included all the volunteer work I did!" And she then described her work as a teenager at their local Center for Independent Living, where she developed her career aspirations and "learned what the independent living movement was all about."

It was always my intent to try to work with individuals who had new injuries. It was a passion of mine to assist persons with new conditions to adjust to those conditions to figure out who they were as a person with a disability and to

recognize that there was a lot of talent and skills that they still had despite whatever barriers they were currently experiencing that would allow them to impact the world, impact society, impact their community and so on and so forth.

Daphne summarized her personal, work, and educational experiences succinctly:

I grew up as a person with a disability... I've interacted with people with disabilities since then, 2 or 3 years old, up through today. I've had various interactions from school to work to training like education to going to college and things of that nature to interacting with community-based agencies... my life basically is that... I wouldn't know a point of time in my life that I didn't have an interaction with a person with a disability.

Daphne gained much of the knowledge she uses through her personal experiences. She has experienced barriers to access in all areas of her life, and she is aware that these barriers can occur in many ways. She has also experienced the internalizing aspects of disability as well. Daphne considered her experiences to be a form of training, and she noted that they slowly morphed into professional training over the years through her occupying volunteer positions and eventually earning college degrees. She also has years of experience in ODS, which she applies in her work. Daphne's personal proximity to disability, and her professional and educational experiences, have all provided her with knowledge that informs her practice in designing and implementing inclusive PSE.

### **Daphne's Beliefs**

Daphne believes that every person can grow with a focus on strengths:

I think that for anybody who exists in this world, they have a talent, and a skill set that just needs to be uncovered and discovered so it can be honed. They can certainly get that through higher education or other means of training.

Daphne also demonstrated a firm belief that growth and development are best enhanced by giving students with ID/DD the freedom to explore along with typical college experiences:

One of the key components of our program is ... “what is a typical student doing in a typical day?” You know, finding the strengths and desires of that individual and maximizing that. That is truly what we want to do and that’s how we set up our program.

Daphne equated the support needs of students with ID/DD with those of any other college student, noting that “if you can find the right hook, for almost anybody, you can motivate them to get moving in the direction that allows them to excel,” further equating students with ID/DD with all other college students; and she said that the best support for students with ID/DD is to “let them live free of ‘you should do this’ and ‘don’t forget that’ although we have coaches there to help come alongside the student”:

If you ask me what kind of curriculum do we use? I would say it’s that we allow them to live life. Yeah. In a nutshell, we treat them like a traditional college student here who has the world as their oyster.

### **Daphne’s Conscientization and Praxis**

Conscientization, according to Freire (1970/2013) is not just becoming self-aware, it is becoming critically self-aware within the context of social and political systems. Gaining this type of critical self-awareness enables individuals to “interfere in

the world which we did not make to the extent that we achieve consciousness of ourselves which in turn is acquired through consciousness of the world” (Freire, 1970/2013, p. 42). Daphne shared an epiphany that she had regarding her own comprehension of her disability in response to a follow-up question regarding how she obtained supports during her K–12 school experiences. The question asked whether at any time during her experiences, she’d thought that someone should have already figured out how to make things accessible for people like her in similar situations. Daphne’s response was as follows:

I did not think those thoughts, honestly, Tami until I was most of the way through my master’s program and I took a course on psycho social aspects of disability and I read in the chapter about how, oftentimes persons with long term disabilities don’t even recognize the ways in which the environment negatively impacts their thinking and their ability to do things that they need to do, and often see it as a problem with themselves because that’s like the medical model and what we’ve always been....that’s how our world’s been built. That was an eye-opening experience for me in that class, because that class challenged a lot of the things that were naturally thinking in my brain even though I didn’t necessarily sign up or subscribe to those thoughts. They just were.

And even to this day I have trouble, and I tell people this all the time. I’m on our faculty senate here at the college, we call it academic council, and you know, we’re doing a lot more inclusion and things of that nature, and I talk about how, it’s like, thank you so much for allowing me to come in this door because you’re so gracious and kind to me, instead of having the mindset that you just

said, which is, this is the way it should be, I shouldn't be, I mean that, I don't mean to be ungrateful either, but it should be this 'aww, aren't they great and special because they think of me and they actually take me into consideration, No, this is the way the world should be built, but I digress.

Daphne's expanded awareness regarding the environmental influence that instilled thoughts that she didn't even know were there yet perpetually influenced her thinking, coupled with her natural penchant for assisting and supporting and her years of experience and education, greatly influenced her ability to foster inclusive PSE for students with ID/DD. Daphne's awareness of her own internalized deficits helped her to be conscious that her students most likely have the same internalized deficits and that students must be supported through the process of overcoming the internalized oppression gained from their prior experiences.

Daphne's praxis, the process by which she used her personally developed theories to enact effective postsecondary practices for students with ID/DD, focuses on identifying and meeting highly nuanced student needs, both external and internal. She connected her prior experiences as a woman who uses a wheelchair and her experiences in special education to her ability to discern supportive inclusive practices. For instance, connecting her own process of critical self-reflection to her students, Daphne's program is designed to provide ample space for students to deal with learning about their own internalization of their disabilities. "It's pretty eye opening sometimes...it's not like a revelation that totally changed all the ways in which I thought, that stuff is so ingrained, it's hard to get it out."



In addition to the knowledge that Daphne gained in navigating life as a person with a disability and her knowledge gained in higher education, Daphne has gained knowledge during 13+ years of working in college disability support, where she helped students get the supports they needed and overcome barriers to success. She recalled when she was “finally mainstreamed” and “I was able to utilize resource support as needed to use the restroom or if I needed a scribe for a test, those types of things, and I used my natural supports as much as possible.” Having had these personal experiences she saw firsthand the value of providing a wide arrange of supports that students can chose from as needed, as well as relying on the natural supports such as other students in the class. She emphasized the importance of getting students the supports they need to access learning, but that supports should not impede learning’s hard work:

We make sure that we provide enough support, but not an overabundance of support that kind of limits and narrows their ability to be challenged and to learn independent living skills that they need to be successful in their community and society. So, you know, we’re not going to go above and beyond what it is that they need, simply because it’s a service that’s available.

Daphne frequently mentioned the importance of considering students’ prior experiences when working with them. Experiences such as bullying, overprotection, limitations, and lack of support of one’s strengths can all have a debilitating impact on a student’s ability to navigate the college experience.

It’s important to have patience. Oftentimes in this world, we want the answer right now. Tell me what you want to do! A lot of our students who are non-ID or non-disabled period have trouble with this question, so I think that individuals

with limited experiences and limited life experiences and the opportunity to have life experiences really need our patience and understanding and maybe the ability to explore above and beyond what may be the traditional amount of time.

Daphne said that her favorite thing in working with students with ID/DD was to see them emerge from their prior negative experiences:

Seeing them interact and slowly finding that it's a safe environment. It's a place where they can learn and also fail and a place where they can get the support they need to be picked up again and encouraged to move forward and learn and be able to get a certification of completion or degree or whatever they get in the end to make a difference in the world that they want to create for themselves out in society. I get excited to interact with students on a long-term basis.

In response to the question "What part of your service or your curriculum is designed to help develop self-determination skills? Do you have a plan for that?" Daphne replied in great detail, explaining that from the very first entrance essay to components embedded within each class, her program focused on developing self-determination skills.

From the get-go. Even before students are accepted into the program, they need to complete an essay... "Tell us a time that you've had to overcome something that was really difficult?," "What is it you want to do?," "Why do you think our program would be good for you?" and that kind of thing.

After the program receives the student's admission essay, the students come in for an interview:

Typically, it's just the student that comes in themselves with the committee and they have to answer seven questions. Some of them are similar to what they wrote about. Some of them are a little bit, you know, offshoots of that. And in that way, we start to see who this student really is and to grab a little bit more of learning them without the influences that others might have. Part of their essay was also writing their life experiences.

After the student is admitted into the program, getting to know the student and helping the student become self-directed is built into a summer bridge program:

We have a summer bridge program that is four weeks long. During those four weeks, they have to work in a team with other classmates or independently or with their coach on creating a person-centered plan. Again, you know, considering who is in their sphere of influence of who is part of their support team. And what it is going to look like in a couple of years. Who is it that they want to be? Do they want to live independently? Do they want to drive? And you know, all of these different things that help to create this plan of what might need to be taken in order to move that student, that person forward in the goals that they're starting to formulate and think about.

Daphne acknowledged that these steps might be small at first, given the limited options and experiences that students have had in making independent decisions and really thinking about directing their own lives:

Sometimes they're miniscule in the beginning because they're not used to, or, they have no idea what to even put down on paper like that. So, we get collaborators and other in there and then, it's a living document. We're constantly

updating it and changing it as the students start to grow and really figure things out and, you know, practice and exercise some of those skills. We see those living documents become even more and more robust and exciting as the students really start thinking through some of those things.

And with the four-week bridge class there is a summer class as well. It's a traditional college course. So, we're challenging them. We're saying, hey, you know, you've got to write a journal. It's a combination of things that will help to remove barriers of what we're expecting that they're going to do in a college course. So, we're always moving the bar forward, and trying to help them start thinking about what it might look like and who they are and what it is that they want to do as they're going through this course. Part of the course is self-discovery.

Although Daphne was a moving force behind her program's design, she was quick to state that "When it comes to student successes, I only provide the opportunity for student A to interact with student B."

### **Summary of Daphne**

As a person with a disability, Daphne has a lifetime of personal experiences in navigating the built environment and educational systems. During her master's program, she became aware of how she had internalized her disability, and she is keenly aware of the internal barriers that students must overcome to grow and develop, as well as external barriers that can be manipulated to support such growth. Daphne's approach includes a safe space and time for internal student development, a variety of supports and educational choices, education for campus faculty and staff to reduce stigma, and the

attempt to acquaint the campus community with the ID/DD population and facilitate interactions with students with ID/DD so that they can continue to grow and be included. Daphne said that in the early stages of planning, the main focus was to determine “what are some of the things that block individuals, entrance, or progress, or ability to be retained.” A core development team explored the issue “from the perspective of K–12, from the perspective of agencies, from the perspective of higher education,” in order to “really get all the barriers out on the table.” The team then explored ways to “break down some of those barriers, overcome some of those barriers, or go around some of those barriers, in addition to...what kind of training or other elements might need to be added as we start having more folks on campus.”

### **Ethel: What is This World?**

“What is this world?” Ethel thought as she gazed at children in restraints perched along the summer camp path. From her memory, she reviewed the scene through a more mature lens of moral outrage, but she had been just seventeen or eighteen years old at the time she experienced it and hadn’t even known that such places existed. “It was intense,” she said, describing the work she did that summer at a camp in New England with children who had emotional and behavioral disorders.

I don’t know any other way to describe it, it was so intense! The physical aspect of it was really intense and demanding. And then, psychologically... We had to experience what it was like to be in a full physical five-point restraint, everybody did, and it was really horrible to experience it, the sense of loss of control. We were trained before the kids got there, and it was always supposed to be last resort, **always supposed to be last resort** [Ethel repeated this for emphasis] and

you're supposed to try everything in your power before you actually put your hands on a kid, but, as the summer wears on, tempers flare, and people are tired, I just know that, you know, that's not always what happened.

Ethel recalled “kind of working through this with my young mind...I knew I felt uncomfortable.” Ethel said that the experience “sparked a kernel in me to want to advocate for spaces where folks would never have to experience that,” and it created in her a drive to create “a space with kids whose voices are not really being heard, and to do whatever part I could to help them develop that piece, so they could be heard.”

Ethel continued working with children with emotional and behavioral disorders and ID/DD in other settings. Each job prompted her to think more deeply about how to help students gain voice and agency, but she looked to her academic studies for her own identity development as a black woman from a dysfunctional family. But she also used these studies to gain skills she needed to help her students develop a voice and to advocate for spaces where their voice could be heard. Ethel's personal growth and development over time foreshadowed her later work in her program, where she currently creates paths for college students with ID/DD to do their own deep identity work and get beyond the limited expectations forced upon them in their earlier educational experiences. Although Ethel initially went to college at an Ivy League school to become a medical illustrator, her academic career became multidisciplinary as she used her education and life experiences to take “every opportunity that I've had to reflect on myself and my positionality and my lens.”

Ethel's educational journey is marked by a series of program selections that were not necessarily the best matches for her interests. She self-reported that making under-

researched college **decisions** is “a theme for me,” but as she moved through her choices, she demonstrated great adaptability and flexibility, utilizing not-quite-right decisions to her advantage. When she discovered that her undergraduate program was not what she was looking for, she considered that she was already “invested...so, instead of picking up and looking for a place that would meet my needs, I was like, let me look at what we have here that is of interest to me. And that’s how I ended up with psychology.” Regarding her master’s program, a program that wasn’t the best fit for her, she said “they didn’t know what to do with me...my advisors were fantastic...they let me really push and I ended up doing a creative thesis which had never been done before...they worked with me and that was great.”

Most of Ethel’s own identity work as well as the work she does with her students is based on a psychological theory that she studied in her undergraduate course work: the theory of possible selves (Markus & Nurius, 1986). This theory involves identity formation, supporting the idea that a central part of being able to expand what one thinks of as one’s own identity consists in being exposed to different possibilities:

At the time my focus was on, you know, women of color, and that for me, being exposed to writers and poets and activists and blues musicians and, uh, women in political power and, like all of that exposure at that point when I was forming my identity was like an essential part of me coming to know, you know, who I am in a kind of broader sense. And if we don't provide folks with those different possibilities, then that impacts the ways in which we’re able to form our identities.

Ethel noted that when she had her first exposure at that summer camp, she “was so young. I knew I felt uncomfortable, but I didn’t really have language for it.” She later noted that “the deeper I got into my program, my PhD, the more language I had for it.”

Ethel’s experiences in working with people with ID/DD elicited feelings in her for which she had no vocabulary. Over time, as she explored her own identity issues through various academic programs, culminating with a PhD in the cultural foundations of education, she developed a language that not only helped her understand her own identity development but enabled her to consider the importance of her students’ identity development. In conjunction with work on students’ identity development, Ethel’s creative gifts allowed her to help students access multiple forms of self-expression, thus freeing them from prescribed modes of communication that might limit their growth and development and maintain a status quo that would recognize only certain forms of communication as valid. “Art is a huge part of my lens” Ethel stated. “I have a huge affinity for collective creative processes...it’s an amazing inclusive approach to the cocreation of knowledge and art.”

### **Ethel’s Beliefs**

Ethel also demonstrated a belief that aligned with this study’s emergent definition of belief, that there is no dividing line between people with or without disabilities and that students with ID/DD are just like any humans, with unique differences that can be supported or hindered by surrounding systems. Ethel said, “People are People. That’s at the crux of everything to me. That people are people, and people have desires in life, skills in life, they have things they need to work on. We all do. Everyone needs support.”



Ethel also noted that the benefits of a college education are the same for any student, whether they have ID/DD or not.

So, I am so passionate about the potential of college education because that discovery piece is like, that's the hugest thing. It's amazing to see students move through that, and come in here and evolve and you know, tap into things that they had no idea that they could do. You know, this is true for any college student. That's what excites me about college is that growth process. But I think for our students, they've been so limited before they get here it's just like the growth that we see is huge and I believe that being exposed to those possibilities, those possible selves is a big part of that.

Ethel demonstrated a passion about removing barriers to inclusive education to ensure student growth:

Students come up against barriers, whether it's attitudinal barriers on campus that are restrictive, or policy barriers that close doors. You know, all those battles that we're having right now to ensure that the campus is inclusive. It's really hard to see a student come in and say "this is something that I'm really passionate about. This is something I really want to be able to do, and you know, they don't have access to it."

### **Ethel's Conscientization and Praxis**

The thread running through all of Ethel's work and educational pursuits was her unique positionality, derived from a willingness to explore intuited thoughts as well as a quest to understand complex identities beginning with her own identity as a biracial black woman from an artistic family. Her personal quest provided her with the knowledge that

her identity work with her students has been based on. In great detail, she described the theory of possible selves developed by Markus and Nurius in 1986:

The theory of possible selves is that in identity formation, a central part of being able to expand what you think of as your own identity is being exposed to different possibilities. At the time my focus was on, you know, women of color, and that for me, being exposed to writers and poets and activists and blues musicians and, uh, women in political power and, like all of that exposure at that point when I was forming my identity was like an essential part of me coming to know, you know, who I am in a kind of broader sense. And if we don't provide folks with those different possibilities, then that impacts the ways in which we're able to form our identities.

I was looking a lot at the time too, especially for children of color, having limited, possible selves, you know, how that impacts how we develop and um, uh, kind of access the broader world. The same is true for anyone of any group who doesn't see themselves. Who doesn't see themselves in a position of power, who doesn't see themselves in the media, who doesn't see themselves in scholarship, who doesn't see themselves...I hold on to this theory, it's a core part of my beliefs on identity. We need that representation. Representation matters and we need to be able to see other folks who are in positions or roles – this is social role valorization- we need to see ourselves in those roles so that we can then begin to access those spaces because it becomes a possibility for us.

Ethel detailed how the theory of possible selves (Markus & Nurius, 1986) provides a theoretical foundation for understanding how some of the primary barriers to PSE for

students with ID/DD impact their growth potential. Primary barriers, according to Ethel, include lack of access to valuable educational opportunities as well as limited opportunities and overprotection. These limitations prevent people with ID/DD from partaking in situations where they can exercise their decision-making skills and learn to self-advocate, and they limit their access to the kinds of valuable opportunities for personal growth and identity development that other students benefit from.

I think that if you don't know that something is a possibility, then you don't have that opportunity to practice and build muscles and build even the components of your identity that would give you access to that role. So, I think that we don't, know, we don't know (Ethel raised her voice for emphasis) for students with ID and DD in this country.

Our educational system it...it... Oh.... [Ethel groans in exasperation] gives us and them no sense of what their capabilities are. Their possibilities or their capabilities. And I do think they are tied, and we see this when our students come in, right? They come in and they say when we ask them, "what are your strengths?" And they say listening, or following directions or, it's just heartbreaking, you know, when they come in the door, this is what they're listing as their strengths. This is what their possible selves are at this point.

Their possible selves at this point are about compliance and about doing what is, uh, that, you know, these really kind of limited, you know, ideas even in career searches they're coming in and it's all about "oh, I want to work in a restaurant," you know, or "I want to work with kids" because that's all they see. Because those are the only possibilities that have been offered to them. And then

they come into this space and they see all of these possibilities that are open to them because of access, so it's that limited menu, right?

And then when they come to college and they have this identity of college student and then they see college students doing all of these things and it opens up possibilities for them which then, because this is a possibility; let me try this.

They may tap into capabilities that they may not have even known that they have, and certainly not the folks who have been supporting them in the traditional sense.

Ethel's positionality was well crafted through her perpetual desire to understand herself and events in her own life, and her self-explorations worked in tandem both to increase her understanding of the social injustice that she had witnessed others face and to be in solidarity with them as she sought to strengthen and support their right to inclusion. Ethel told of her own experiences with disability as well as the challenges of being a black woman.

When she was in her twenties, Ethel experienced mental health issues, including a misdiagnosis, unneeded medications, and unhealthy therapy. She had been struggling with "some really problematic parts of my family background...it was not the healthiest in some places and in other places it was great, but there were some really unhealthy parts of my background that impacted my mental health." She connected these experiences with her developing understanding of stigma.

My twenties were tough and that certainly impacted the way that I engaged with the world and the way the world engaged with me. So I experienced the shame that comes with stigma, you know, of having a mental health diagnosis, and, you know, just the social, what that means; socially having to talk to people about it

and tell people about it and divulge, you know, your disability. I understand that kind of through lived experiences...and I know that not everyone understands when you're in those places how difficult it can be. So again, having to advocate for yourself, and having to be gentle with yourself, and all those kinds of things. Regarding how her race and gender helped her develop a critical stance, she said

And then I would say the other way, when I think about that, is certainly race. I would say the fact, just being a black woman, being a black woman in the academic world is challenging. Just being a black woman period. I have a 20-year-old son I worry about every day. I'm fearful of what he's going to encounter in the world, so there's race, definitely part of it. And then the other thing I would say it that I don't really consider this a disability, but just my lens. My lens being more critical. Yeah."

Ethel reflected that she has always had "a kind of disgust with the educational system and the way it "others" and it silences and discounts and labels and targets...you know...I always feel other in those spaces." But she noted that "the deeper I got into my program, my PhD program, the more language I had for it, yeah, and understanding of the system and what's going on, and you know, at the macro level. So, there's knowledge of what's happening along with my experience for myself in the space of being othered and feeling that very keenly."

Ethel's 25 years of working with children and adolescents with ID/DD have given her hands-on experience and training focused on disability, but she did not focus on disability in her academic studies; instead, in her studies she sought support for her personal growth and identity development.

Ethel's own identity work and her creative work with students with ID/DD eventually became enmeshed in her doctoral studies, which gave her the opportunity to examine education's role in maintaining the status quo for marginalized populations from multiple perspectives (e.g., philosophical, sociological, historical). Her dissertation focused on providing the space for students with ID/DD to express themselves through creative platforms. She credited her doctoral program with having "pushed me to trouble this idea of inclusion, of what inclusion really means," and she added that university services for students with disabilities are still grounded in a medical model of disability.

When you look at the world of accommodation, particularly at the university level, it's still steeped, it's still anchored in the medical model. It is just so frustrating to me to see the students, whoever they be, whether they/re students I'm working with or not, to have to go in and prove, **and prove**, (Ethel repeated for emphasis), that they have the prerequisite deficits to be able to be eligible for support. I just, that just absolutely makes me crazy, you know! Rather than, can we look at our pedagogical practice? Could we look at, you know, universal design and just a more engaged practice where we are teaching everyone so that you don't have to go in with your hand out or with your hat out, you know, and say 'I deserve support.' What is that about!?

### **Summary of Ethel**

Ethel's personal experiences with diversity and disability spurred her educational pursuits, particularly with respect to identity development. Those pursuits also supported her work with individuals with ID/DD to help provide spaces for them to express themselves and develop their voice and gain agency as a prime focus of her work.

Currently she works in curriculum development for her program. Her dissertation was based on students' creative representation of their college experiences, assembled through participatory action research. Ethel also pointed out that the idea of "giving students voice" suggests a false power dynamic, when, students already have a voice, we merely create spaces for those voices to be heard. Ethel was not part of her program's development team, but she was hired as one of the first coordinators when the program opened. Experimentation and out-of-the-box thinking supports her work. As she said, "We've been around and tried a lot of things and we've learned; experiential learning. We're building the plane as we fly it!"

### **Lori: Heck, I Can't Wait to See What's Next!**

Lori straightened her plaid Catholic School uniform as she stood outside the classroom door. It was her first day volunteering at an afterschool arts and crafts program for young adults with intellectual and developmental disabilities. She'd never spent much time with anyone with a disability before, she'd seen people who "look like them" but had "never really encountered them." Nevertheless, for some reason, her 4-H leader thought this would be the perfect volunteer project for *her*, and she had been cherry picked for it! She looked through the window at the classroom already bustling with activity and realized that she had no idea what to expect.

Lori took a deep breath. She stood up tall and raised her fist to give a firm knock on the door. She watched a young, stocky man with Down syndrome come over to the door to let her in. He had a big smile on his face and appeared to be about her height. After he opened the door and said "Yes?" with an expectant look on his face, Lori jumped right in to introduce herself. "My name is Lori, and I'm here to see Mr. Kern,"

Lori said as she took the young man's extended hand and let him guide her into the room. He replied, "My name's Eddie." After a firm handshake, they set off to join the other students on the other side of the room. They hadn't gone far when Lori realized that Eddie had other plans. Without any warning, Eddie seized Lori, threw his arms around her like a big bear and then flipped her over a desk in a tango like embrace. Without missing a beat, he proceeded to plant the biggest, wettest kiss on her forehead that she could ever have imagined.

In a flash, the room sprang to life. Mr. Kern, the head teacher, rushed over and grabbed Eddie by the back of his shirt. As he pulled Eddie off Lori, he yelled "Eddie, that's not the way that we talk to people who come to our class, go to your seat!" Eddie responded with a deluge of tears and skulked back to his seat, while Mrs. Ames, the classroom assistant, ran up to Lori with a wet nap hoping to calm her down. "Oh, sweetie," she said, "sit down here and let me get you cleaned up!" Sitting in the midst of this sudden, chaotic action, Lori thought to herself "What the heck have I gotten myself into?"

After class, Mr. Kern walked her outside where her ride was waiting. "I wouldn't blame you if you didn't come back next week," he said, acknowledging the craziness of her entrance. At home, her mother also reassured her that she didn't have to go back if she didn't want to. But something about this experience resonated with Lori and she dismissed their concerns. "Heck, I can't wait to see what's going to happen next, I'm coming back!" And that is how Lori became interested in a career in special education, a job which she referred to as "The bomb job!"



Although Lori did not have prior personal or professional experience with individuals with ID/DD or identify as disabled or marginalized in any way, she felt an instant affinity for working with this population. Lori's enthusiasm for her job stood out during her interview, and she especially enjoyed personal relationships that she developed with people with disabilities over the years. Lori reflected on her 30-plus year career in special education as follows:

It all comes down to what it is that makes me happy or has made me happy. And being successful as a teacher was my goal. I mean truly it was to be a good teacher and to make a difference. So, I could have been, I guess, if been good at math or science, I could have had that as my goal. But I think I'm really good at teaching individuals with disabilities to do what it is that they need to do. My self-gratification basically. Truly – I think I wanted to be happy with what I was doing. And what makes me happy? Being successful. And what am I successful at? Working with people with disabilities.

In summary, Lori did not identify in any way as disabled or diverse and came to the field through volunteer work in high school. She has three degrees in special education and stated several times that it was valuable to have a credential. When Lori discussed her past career, education, or program, she only mentioned the students a few times, and associated her knowledge of special education with her credentials and to opportunities that her career gave for her to grow as an instructor and scholar. Lori had concrete knowledge and awareness of how the special education system operates in relations to policies and practices, including knowledge of how the system can fail to accomplish the work it set out to accomplish.

## **Lori's Beliefs**

Lori demonstrated her belief in the growth and development potential of students with ID/DD by relating several stories about student's growth in the program. She noted that "students with ID/DD are just a different permutation of us" and that "they're not as different as you think." This is one of her stories about students' growth:

The story of Steven stands out in my mind as the most recent success. Steven came to our program here after having been homeschooled. He was home school because his parents wanted to protect him. I'm not sure that it was warranted, but nevertheless, that was their approach. So, he came here and was scared to death. First of all, he was scared just to have to be in a, a university; second, that he had to use technology that he didn't know how to use. Like he needed to use a smart phone and needed to use a laptop because those are requirements for our program, and there were lots of people who were talking to him and asking him questions and asking his opinion. And those were just really scary things 'cause people just told him what he thought prior to this. So, there is Steven on his first day, two years ago, and here's Steven today.

I saw Steven two weeks ago, and I asked him how are things going? He says, well, he's taking an environmental class on global warming and environmental impacts. And I said, "wow, who's teaching that?" "Oh, it's in the honors college." I said, "are you taking it for credit?" And he said, "no, not this one. I'm auditing it." And I said, "great! So, what's the major project?" He said, "Well, we have to do a research project. I decided, I'd ask if I could do a PowerPoint."

Lori explained that the program had developed courses to support the development of students' self-determination skills; however, unlike Daphne and Ethel, she made no mention connecting this course development to an understanding of prior experiences that students might have had which limited their growth and development, nor did she emphasize establishing a better understanding of students as being a component of the program that had any more importance than any other. In fact, Lori mentioned that one of their program's main staff was a "curriculum expert," and said "thank God we have the curriculum. They're not creating anything new for right now," which indicates that the program isn't attempting to continually adapt and modify as student needs become apparent.

### **Lori's Conscientization and Praxis**

Lori was the only participant in the study who did not identify as having any proximity or personal experiences with disability, racial or ethnic minority, or any other type of marginalized experiences. When I asked about her education, she stated, "I have three degrees in special education." When I pressed for details, she further described her educational degrees and offered reasons for some of her choices based upon monetary benefits.

I have a bachelor's in special education from State U., K-22, mentally and physically handicapped, a bachelor of science, I have a master's from State U. in special education. I returned to the same institution because they would allow me to work with preservice teachers as a master student, so I figured that was a good chance to supervise student teachers, and they paid for my degree! My doctoral is

in special education and rehabilitation from U. of State, with a focus on transitioning from school to work.

Lori's response was surprising, because, when discussing their educational experiences, all the other participants immediately provided some type of personal story regarding their educational choices and experiences. The other administrators talked about why they had pursued a certain course of study, what they had hoped to learn in their programs, or how their studies connected with their work with students with ID/DD. The only connection Lori made with work was that having a credential was valuable. When I attempted to press her further about her education, swapping the word *training* for *education* in the hope that it might prompt a new memory, she responded, "I have three degrees in special education...so training...I have many university credit hours in special education for teaching. So that includes characteristics, the nature and the need, specifically in working with transition age youth with ID/DD as part of my doctoral and master's work."

Lori noted that the wide variety of experiences her job encompassed "kept me from being bored." It became apparent throughout our interviews that Lori's personality was a big part of her job, and that she had selected a career that made her happy—one for which she has a suitable disposition and skill set.

Throughout her three interviews and subsequent follow-up questions, Lori exhibited a vast practical knowledge regarding the systems, policies, and practices that form the structure of the special education system as well as practical aspects of working with students with ID/DD such as using concrete language to convey information, however, she rarely spoke of the students themselves, and when she did, she referred to

them diminutively as “kids” and “kiddoes.” When I asked her to “describe for me a successful moment that you had working with an individual with intellectual disability,” she told of the growth of a student in her program (Steven’s story), but she did not explain how she or the program were connected with that student’s growth. When I asked her to describe a moment that didn’t go so well, she referred to an incident she had with a parent in her first year of teaching in which she and a student’s parent had a disagreement regarding a course of action she thought was best for the student. She said this incident helped her grow as a teacher, but she did not mention any direct impact, positive or negative, that she had as a result of her work with students.

This was, in part, due to her teacher training role in which she was not working in the classroom, but still stands in stark contrast to Ethel, who described a time when she helped a young man with early language development, or Daphne, who described extensively the way her program worked to provide natural supports and help a student get the classes the student wanted. Emilia also described a breakthrough in communication she’d had with a little boy in central Mexico. When I asked Jane to describe a successful moment, she said, “I have millions of them,” and she proceeded to tell several stories, one of which involved how the program taught a young man to be self-supporting and live independently after he exited the program.

Because the responses I received from all the other participants were so qualitatively different from Lori’s, in my third interview with Lori, I attempted to focus on social justice issues which had so spontaneously surfaced in interviews with the other administrators. My original interview protocol was specifically designed to not ask leading questions about social justice and included open ended questions. I considered

that, perhaps, Lori was very literal and had been answering the questions verbatim, directly responding to the specific question asked. She did this for all my follow-up questions as well, providing one sentence answers to probing questions. In the third interview, I began to specifically probe in this area, and I asked her, “somewhere along the way, did you start to see that there were things that were unfair for this population and can you talk about those times?” Lori replied by immediately changing my term “unfair” to the term “uneven” negating the concept of injustices and choosing a word that merely indicates a lack of uniformity, rather than inequity. She then added the following detailed response.

So, what you’re talking about is understanding whether or not I ever realized that there was an unevenness with those individuals [who] were served? Initially, no, that wasn’t the case. Of course, as you know, I was a kid doing volunteering things and so it wasn’t like I was knowledge about how things operate in the bigger picture of federal legislation and school district policy and who gets served. So, the understanding about a free appropriate public education, that’s all part of what I learned when I became a special ed teacher. So, it was really important for me and for my overall professional development to learn all those things that you students can start to roll their eyes at and might think “Why do I need know about the Carl Perkins Vocational Rehabilitation Act, Oh really?” you know, but the deal is that when you know those things, then all of a sudden it’s kind of like, Hey, I don’t see that happening.

So that’s the gist. I don’t see it happening. Why isn’t this happening?  
Where can we go to make it happen? If we’re talking about inclusion in K–12,

why isn't it inclusion in higher ed? If you think about the least restrictive environment with age appropriate peers, where are the 18- to 22-year-old individuals? They're not in high school. The 18- to 22-year-old individuals without disabilities are in college. So why aren't those kiddos with special ed who are still allowed to be in school because of their unique disabilities, why aren't they with people who are their same age peers, right?

So, yeah, there was a time, and I can't tell you the moment, the minute, or the day, but I know that there was a point in time when it all started to become clearer to me that when we're talking about inclusion. talking about inclusion only for K-12. We typically don't talk about what does inclusion look like for folks in higher ed. And when you start to talk about inclusion for people in higher ed, then what you start saying is, Hey, go to college? You have to take the SAT and all that stuff. Well, then you start to work on those peculiarities of the program. I am sure that other people do this very same thing and I'm sure that they give up because it's fraught with an uphill climb and disappointment. That's why I was kind of like, oh, just one more thing, just one more thing that I have to do to make this happen. I mean, why can't it be simple? It's hard. Hard stuff, so you give up. I'm happy to say that I tried not to give up and kept at it until we were able to have something happened.

In response to my question "disability cuts across all socioeconomic sectors and factors. In your experience, how have you seen students' backgrounds affecting their services?" Lori explained;

Well, here, it's like anywhere else. There are schools that are funded in a much wealthier areas and higher tax bases, and like it or not, they get better teachers because the schools are nicer and there's extra programs that attract the students. So, unless the school district is attending to those kinds of inequities by having busing or allowing students with disabilities to travel around the county to get to the programs they want, it's like everybody else. It happens in some cases, but it doesn't happen in every case...and parents need to know how to negotiate the system.

While Lori was able to clearly articulate what she referred to as “uneven” services both in policy implementation and in the uneven distribution of resources within a school district which she articulately tied to wealth distribution and parental negotiating skills, she maintained a stance that merely declared what was apparent and did not problematize these circumstances by looking deeper into the root causes of these circumstances. Therefore, her use of the term “uneven” rather “unjust” or “unfair” indicated her non-critical stance.

### **Summary of Lori**

Lori's demonstrated care and concern for students with ID/DD and a vast knowledge of program design and implementation; but she did not seem to approach her work from the perspective of social justice or educational equity, and she attributed the concept of inclusive higher education to an extension of inclusive K–12 laws. In describing problems that her program had securing funding, she noted;

We were fighting a process that wasn't even articulated by the federal government yet. We were trying to establish a program that was not supported by the federal



government because the HEOA wasn't signed until 2008 and then, not articulated until a little bit later. And then, you know, now we have people understand that comprehensive transition programs for people with intellectual disabilities fit in title four, but at that point, it was like talking Swahili or some other really unknown language.

### **Analysis: Daphne, Ethel, and Lori**

In this section I discuss the impact of Daphne, Ethel, and Lori's personal proximity to disability or diversity, their professional experiences, and their educational experiences and how these experiences impacted their approach to designing and implementing inclusive PSE for students with ID/DD. In the next section, I extend these findings to include all nine participants, in support of my main findings.

#### **Proximity to Disability**

The main influence on Daphne's professional practices consisted of her personal experiences with disability. The main influence on Ethel's professional practices was her identity research. The main influence on Lori's professional practice was vocational suitability. Highlights of Daphne's practices were (a) gaining understanding of students' needs and attempting to remove any type of barrier to college access without over-supporting, which can prevent growth; and (b) respecting the student's internal struggles and the impact of past limitations. Highlights of Ethel's practices were (a) foregrounding student identity development and (b) supporting students' exploration so they can see opportunities and possibilities of what they might become. The highlights of Lori's practices were (a) developing all program components and (b) hiring knowledgeable staff whom she referred to as specialists.

## **Impact of Professional and Educational Experiences**

Here, I explore these differences in light of professional and educational experiences. For Daphne, there was no separation between her personal experiences and her professional experiences; she noted that she had gained knowledge from her personal experiences and that her professional experiences began as volunteer experiences closely associated with her personal experiences. Daphne also noted that she selected her degrees to support her desire to counsel individuals with disabilities, but that changes in the law and degree requirements ended her educational pursuits because she needed to find a job and begin working. Daphne frequently talked about barriers to access and students' internal struggles in her interviews, and she described how her program addressed these barriers.

Ethel's first professional exposure to individuals with disabilities resonated with her deeply. As she said, it "sparked a kernel in me to want to advocate." This empathetic start to her career led to a symbiotic relationship between her studies focused on identity development and her professional work to support individuals with disabilities. The accrual of her academic knowledge supported her hands-on work with individuals with disability, which in turn guided her academic studies. Ethel frequently talked about barriers to access and students' struggles in her interview as well, and she described barriers and how they were overcome. Additionally, she focused on curriculum content in supporting student identity development.

Lori's first exposure, an unexpected volunteer position in high school, resonated strongly with her in terms of her personality and career fit. She pursued employment and education solely in the field of special education from that moment on, attaining the

position of a tenure track professor in special education. Most of Lori's professional life was spent training and supervising special education teachers rather than being in the classroom with students herself. In referencing her academic and professional lives, Lori frequently commented that she was lucky to find a career she liked so much, that it kept her from being bored, and that she liked troubleshooting problems to find solutions.

Lori's position was solely administrative, and she talked primarily about her program's structure. When mentioning direct contact with students she said that she's the one who helps "getting the students jazzed about something...I'm the person on the side." The only time in which she mentioned students' internal struggles, she discussed them as though they were something that students had control over and used purposefully to manipulate their situations rather than being subconsciously ingrained behaviors resulting from prior experiences (internalized oppression). "It's the stereotypes the person with the disability holds" she mentioned in listing barriers, and in response to another question, she referred to students' trying to use their disability as a crutch to get out of doing work. Lori described her program in exacting details but never mentioned how it specifically considered students' experiences. She stated that everything was so much easier once the program had established its curriculum: "Thank God we've got the curriculum."

### **Summary of Daphne, Ethel, and Lori**

The main influence on Daphne's professional practices consisted of her personal experiences with disability. The main influence on Ethel's professional practices was her identity research which led to critical and cultural studies in education. The main influence on Lori's professional practice was her vocational training and professional

experiences. Highlights of Daphne's practices were (a) understanding and attempting to remove any type of barrier to college access without supporting too much and preventing growth, and (b) respecting the student's internal struggles with past limitations.

Highlights of Ethel's practices were (a) foregrounding student identity development and (b) supporting student exploration. The highlights of Lori's practices were (a) developing program structure and (b) hiring knowledgeable staff whom she referred to as specialists.

### **Cross-Case Analysis: All Nine Participants**

In this section I compare the beliefs, experiences, and practices of all nine participants. The stories of Daphne, Ethel, and Lori present the strongest cases demonstrating the connection between proximity to disability or diversity and inclusive PSE practices, the connection between having had critical studies to inclusive PSE practices, and the connection between having neither proximity to disability nor diversity nor a critical education on inclusive PSE practices. These three factors are now used for a cross-case analysis of all nine participants.

During cross-case analysis, it became evident that one administrator, Lori, stood out distinctly from the others. Lori was frequently the only administrator who answered multiple questions in a qualitatively different manner than the other administrators. In the following cross-case analysis, I refer to administrators as a conglomerate numerical group except in instances where only one person had a different type of response. In those circumstances, I identify the participant by name. I do this to establish Lori as divergent case, which, according to Skipper et al. (1993) helps maximize the range of data. Further discussion of this divergent case is located in the discussion section of chapter V.

## **Beliefs**

All nine participants indicated beliefs in the human growth and development potential of students with ID/DD. These beliefs were examined in this chapter to provide the following construction of beliefs: (a) administrators of inclusive PSE programs know through experience that students with ID/DD have the power to grow and develop like all other college students, and (b) administrators of inclusive PSE programs consider students with ID/DD to be just like all other humans and respect their unique differences noting that individual differences can be supported or hindered by surrounding systems.

## **Oppressions**

All nine participants understood the external oppressions that contribute to student deficits (e.g., dumbed down curriculum, exclusionary practices); however, only eight of the nine participants recognized that students internalize these external oppressions and come to college with self-beliefs that might not be rooted in their actual abilities and that may have hindered the growth of their ability to be self-directed, to make choices, and to experience activities normally associated with students their own age. Lori, noted some of the same outward manifestations of internalized oppressions as the other administrators such as students lacked self-confidence, were afraid to try new things, had a fear of failure, were being in basic skills, or didn't apply themselves to the coursework. While the other administrators attributed many of these behaviors to a life-long of being provided limited opportunities to grow in these areas along with the message that they were incapable, Lori, however, did not attribute these to inward changes (internalization) in the student that resulted from oppressive situations and for which special considerations should be made regarding their support. Instead, Lori approached these

less desirable behaviors more as controllable character traits that students had control over and at one point, she mentioned that students sometimes use their disabilities as an excuse to avoid work and teachers shouldn't let them get away with that.

Eight of the nine participants took a critical approach to inclusive PSE. They sought to determine root causes of barriers and exclusion, such as biases or prejudices, unfamiliarity with the ID/DD population, and other factors related to socially exclusive and unjust attitudes that can deny access to PSE for students with ID/DD based on student characteristics and do not recognize the students' growth potential or view inclusive PSE as a humanizing movement. In describing their programs, these administrators discussed fine-tuned components developed to meet students' needs, as well as an educational posture turned toward deepening understanding and finding new and better solutions to overcoming social inequities faced by students with ID/DD.

Lori, however, described each barrier as a localized situation to be surmounted in a local context rather than exploring the roots of each barrier to determine whether it reflected biases, prejudices, or other factors related to socially unjust attitudes towards individuals with ID/DD. This administrator labelled all the parts and roles needed to construct a program and noted that once all those pieces were in place, the program was easier to run. While discussing this program, the administrator did not indicate any practices that were based on the assessment of students' needs but did indicate compliance with CTP standards as a guiding rule.

Five of the nine administrators used critical language to discuss their practices stating that their approach to inclusive PSE promoted students in gaining "voice" and "agency." Three administrators did not use critical language, but nonetheless described

critical factors such as recognizing that students were presented with dumbed down curriculum, endured exclusionary practices, and were provided with limited opportunities to learn, grow, and develop. Lori, however, did not use critical language to describe her practices and, although, she referenced issues that could be considered critical, she did not present them as problematic, instead, describing injustices as immovable status quo.

Table 4 presents descriptive data for all nine participants, with the addition of categories indicating if they took a critical approach, used critical language, had educational experiences that included course work or self-study in critical studies or social justice, and whether or not the participant indicated having undergone a process of conscientization (critical self-reflection).

**Table 4***Overview of Participant Findings*

Participant	Personal Experiences	Professional Experience	Critical Studies	Education Formal	Conscientization	Critical approach	Critical Language
Daphne Age: 40s 2-year, Public CTP	Yes Self	Yes	No	BS, Rehabilitation services MS, Rehab. Counselor ed.	Yes	Yes	No
Ethel Age: 40s 4-year, Public CTP	Yes Relative, Self	Yes	Yes (Formal)	BS, Psychology MS, Communications PhD, Cultural foundations of education	Yes	Yes	Yes
Lori Age: 60s 4-year, Public CTP	No	Yes	No	BS, MS, PhD, Special education	No	No	No
Maggie Age: 60s 2-year, Public CTP	Yes- Parent of disabled child, Self	Yes/Second career	No	BS, MS, Applied psychology AS, Disability support	Yes	Yes	No
Emelia Age: 30s 4-year, Public, CTP	Yes Relative, Self	Yes	Yes (Informal)	BS, MS, PhD, Special education	Yes	Yes	Yes

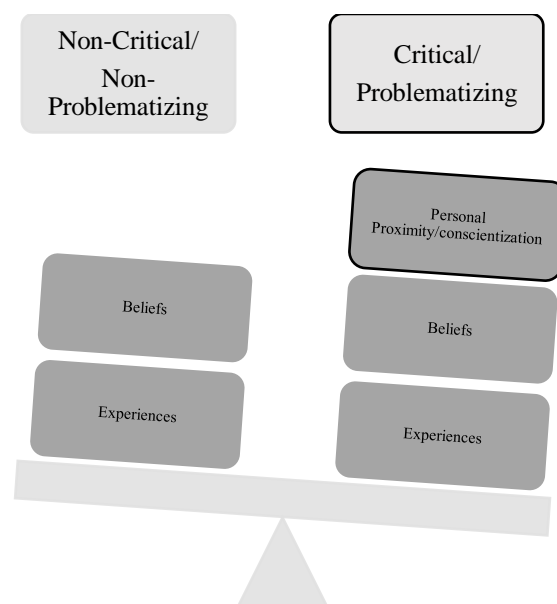


Table 4. Continued

Jane Age: 50s 4-year, Public CTP	Yes Relative, Self	Yes	No	BS, Special education	Yes	Yes	No
Javier Age: 60s 4-year, Public CTP	Yes Relative,	Yes	Yes (Formal)	BSW, MBA, PhD	Yes	Yes	Yes
Rachelle Age: 30s 4-year Private	Yes Relative	Yes	Yes	BS, Biology, MSW PhD, Special ed, program administration	Yes	Yes	Yes
Bobbie Age 30s 4-Year, Public	Yes Relative, Self	Yes	Yes	BS, Psychology MS, Behavior analysis, MEd, Special ed. PhD, Special ed.	Yes	Yes	Yes

*Note.* Personal experiences include both experiences with disability and diversity or marginalized experienced, and diagnosis of disability may be observational or experiential and may not be a medical diagnosis. Some formal education experiences may have contained critical or social justice components.

The data in Table 4 suggest a connection between disability and diversity (i.e. marginalizing experiences) and between conscientization and administrators' critical or non-critical approach to inclusive PSE program design and implementation. The only administrator (Lori) who did not take a critical approach was also the only administrator who did not indicate having undergone a process of conscientization or critical self-reflection. She was also the only administrator who indicated no prior personal experience with disability or diversity before coming to the field as a practitioner (albeit through volunteer work). Figure 2 illustrates these tentative findings which indicate that beliefs and professional and educational experiences alone may not contribute to a critical approach, but that beliefs and professional and educational experiences coupled with personal experiences with disability or diversity and practicing critical self-reflection may prompt administrators to take a more critical approach (See Figure 2).



**Figure 2**  
*Factors Contributing to a Critical Perspective*

Further analysis revealed an additional connection between administrators' educational experiences and use of critical language with respect to power, agency, bias, and prejudice, which helped them describe their perceptions of critical experiences more accurately. Ethel sought education to help her understand critical educational issues and pursued a PhD in cultural foundations of education, which she noted "was really instrumental in the continued evolution of my own personal philosophy and epistemology around disability and pushed me to trouble this idea of inclusion." Bobbie and Rachelle noted that social justice was woven into their curriculum or institutional mission. Javier and Emilia both pursued knowledge about social justice outside of formal education. Javier pursued education at the Highlander Research and Education Center, and Emilia learned from colleagues: "I have amazing colleagues in cultural studies in education" she said. "So, I'm learning a ton from them...finally getting that foundation and the language I've been probably looking for for the past 15 years." Daphne made it clear that a lack of a succinct, critical language was detrimental in her ability to explain her experiences, interjecting in her interview that "I'm fumbling with my words," "I don't like that word either," and "I hate the words we use to describe these things." Lori also demonstrated a lack of critical language by perpetuated the infantilizing of students with ID/DD by referring to them as "kiddoes" and while conceptualizing each step of program implementation as a "battle" and "uphill climb" did not refer to deeper systemic issues that might be the source of these difficulties.

### **Chapter Summary**

In the vignettes, the stories of Daphne, Ethel, and Lori represent the most pronounced findings from the study—the impact of personal proximity to disability and

diversity (marginalized experiences) on practices, and the further impact that pursuing studies in social justice or critical inquiry can have on expanding a critical awareness and developing a critical language. I introduced Daphne, Ethel, and Lori holistically first, tying together their personal, professional, and educational experiences. I then added a discussion of their beliefs, conscientization, and praxis, demonstrating how their experiences seem to have an impact on their practices. These cases serve as exemplars indicating that personal experiences with disability or diversity, along with the process of conscientization, can help build administrators' awareness of the internalized oppressions that students with ID/DD bring with them to campus. This increased awareness develops a solidarity with their students, inducing administrators to create practices that help students with ID/DD to do the deep psychological work needed to overcome internalized oppressions and to continue growing as a college student. Administrators who lack experiences of marginalization at the personal level and who have not gone through a process of conscientization are still aware of and capable of setting up systems and processes needed to establish inclusive PSEs; but these administrators may not be aware of the necessity for creating programs and practices designed to support the internal healing that students need to do to work through their internalized oppressions. This non-critical view may inadvertently perpetuate a limiting status quo by extending special education practices from the K–12 system to college campuses rather than creating transformative experiences for students. Additionally, a non-critical, non-problematizing approach to barriers considers them to be anomalies rather than to prompt a critical examination of underlying systemic injustices.

Finally, in the cross-case analysis, I examined the findings across all cases. This analysis indicates that the personal, professional, and educational experiences of administrators do have distinctive impacts on their practices. Administrators who connect their personal experiences with disability or diversity and marginalized experiences and who are critically self-aware regarding the impact that these experiences have on them are better able to understand their students' marginalizing experiences contributing to an increased solidarity with their students evidenced by the provision of practices that accommodated students' need for internal growth and transformation. Although these administrators had an intuitive critical awareness of social injustices their students faced, they lacked a critical articulation of these injustices. Administrators who pursued education in social justice or critical studies developed this critical language along with a critical lens for examining inclusive PSE, which was evidenced in their practice by a concerted focus on eliminating biases and prejudices, normalizing inclusive PSE, and creating curricula designed to help students become self-aware and access all the available opportunities on college campuses to maximize their growth and development during the college years.

## **V. DISCUSSION, IMPLICATIONS, AND RECOMMENDATIONS**

### **Introduction to the Discussion, Implications, and Recommendations**

My purpose for conducting this study was to explore the personal, professional, and educational experiences of inclusive PSE program administrators and their beliefs about students with ID/DD to learn how these experiences and beliefs might impact their work designing and implementing inclusive PSE for students with ID/DD. This chapter includes a discussion of the major findings connecting these findings with prior research in the field of inclusive PSE for students with ID/DD and DE, with broader contextualization in educational preparation and the role that critical self-reflection plays in developing critical awareness. Findings also reflect the use of a critical conceptual framework derived from the educational philosophy of Freire. The chapter concludes with implications for further study, recommendations for the fields of inclusive PSE and DE, and a brief summary.

Overarching RQ: How do the personal, professional, and educational experiences of administrators of PSE programs for students with ID/DD and their beliefs about the human growth and development potential of students with ID/DD impact their work in the field of inclusive PSE?

RQa: What are the personal, professional, and educational experiences of administrators of inclusive PSE programs for students with ID/DD?

RQb: What do administrators believe about the human growth and development potential of students with ID/DD?

RQc: How do those experiences and beliefs impact administrators' work in the field of inclusive PSE?

## **Summary of Findings**

All nine administrators in this study reported having similar beliefs about students with ID/DD which contributed to the construction of the following definition of administrator beliefs; (1) that students with ID/DD have the capacity to grow and develop like all other college students, and (2) that students with ID/DD are just like all other humans with unique differences that can be supported or hindered by the surrounding environment which includes social, political, and educational systems. All nine administrators gained this knowledge through first-hand personal or professional experiences. An important component of knowledge gained through personal and professional experiences was a developed awareness of multiple types of external oppressions that can limit the growth and development of students with ID/DD.

In addition to developing an awareness of external oppressions (i.e. lowered expectations and limited opportunities for learning), the administrators who had experienced conscientization, a process whereby they critically examined themselves in relation to their own marginalizing experiences or positions of power and privilege, demonstrated a more highly developed and complex understanding of student oppressions, particularly regarding the internal damage that external oppressions may have on their students with ID/DD.

For administrators who had experienced conscientization, their knowledge of students' internalization of external oppressions prompted an adjustment of practices that took into consideration student's psychological adjustments as they became college students. Administrator sensitivity to internalized oppressions and psychological adjustments informed their practices prompting them to provide additional support for

students. Such supports, for example, included providing safe spaces and additional time for students to grow and adjust to their new environment. This response stood in opposition to administrators merely responding to outward manifestations of behaviors and considering them to be either character deficits or behavior issues. In addition to having experienced conscientization, administrators who pursued education in social justice or critical theory in which they studied systemic power imbalances (i.e., social, economic, political, and historical) had developed a critical lens with which to scrutinize their work and they had also developed a critical language that facilitated their ability to precisely express critical issues such as internal oppression. Freire (1970/2013), Tatum (2013), and Bell (2013) all refer to the damaging impact of the internalization of oppressions and Freire and Bell particularly emphasize the importance of considering theory and practice to “demonstrate interconnections among different forms of oppression and suggest common strategies to oppose it collectively” (Bell, p. 23).

### **Interpretation of the Findings**

Inclusive PSE for students with ID/DD is a novel and emerging field in higher education focusing on equity and access issues for a highly marginalized and vulnerable population. Student benefits have been widely studied (Moore & Schelling, 2015; Ross et al., 2013) and the movement has gained momentum with federal funding (HEOA, 2008) and dedicated research and support (Think College, 2020a). Program design is now being addressed more directly in the literature (Baker et al., 2018; Francis et al., 2018) and, although administrator tasks are being compiled (Bumble et al., 2019) research exploring administrators’ backgrounds and qualifications has not yet been conducted. The administrators in this study expressed that there is a need for this type of exploration due



to the large array of skill sets required to implement an inclusive PSE program. In this study using a critical lens to explore administrators' experiences and beliefs, the following themes emerged; (1) administrators have beliefs that are grounded in their experiences, (2) administrators have knowledge of student oppressions that are grounded in their experiences, (3) administrator conscientization impacts practices, and (4) administrator's exposure to social justice and critical studies impacts practices.

These four themes have the potential to inform future development of administrator competencies in this novel administrative role. The purpose, however, of the study was to bring a critical lens to their experiences in order to understand how experiences impact practices. To do so, each theme was explored within the existing literature on critical studies and administrators' beliefs in K–12 special education, developmental education, and social justice education.

### **Beliefs**

*While the problem of humanization has always, from an axiological point of view, been humankind's central problem, it now takes on the character of an inescapable concern."*

(Freire, 1970/2013, p. 43)

The first finding in this study is that administrators' beliefs can be operationalized as a byproduct of knowledge gained through experience with ID/DD. This operationalization includes (1) that students with ID/DD grow and develop like other college students and, (2) that administrators hold attitudes in which they consider students with ID/DD to be another permutation of human variation. This finding connects administrator beliefs and experiences with other research that documents the growth and

development of individuals with ID/DD across the lifespan (Karmiloff-Smith, 2009). Javier mentioned that students in college adapted to situations they may not have been exposed to prior to their PSE experiences including spending the night away from home. Examples range from making simple daily living choices to complete emancipation. Simple choices were evidenced when Lori told of the young man in her program, who, at the age of 26, learned to make his own daily clothing choices rather than allowing his mother to, and self-advocated for doing so. Full emancipation came to the young man in Ethel's program who, through development during his years in her program, demonstrated to a court of law that he'd gained the skills to self-govern lead an independent life and no longer wished to be a ward of his parents. This developmental approach across the lifespan also aligns with the philosophical foundations of developmental education (DE) (Alexander, 2010; Arendale, 2006) and is a central concept of Freire's educational philosophy which he calls humanization – the act of becoming more human. Administrator belief in the growth and development of students with ID/DD also aligns with research on the benefits of inclusive PSE for students (Flannery et al., 2008; Forrester-Jones, 2004; Migliore et al., 2009; Prohn, 2014; Qian et al., 2018).

In holding these beliefs as a foundation for the work they do, administrators also demonstrate an alignment with the human rights model of disability that was adopted in 2006 by the United Nations Convention on the Rights of Persons with Disabilities (U. N. General Assembly, 2006). The United Nations Convention on the Rights of Persons with Disabilities outlines that access to education for every human is “a fundamental right of all learners” (Convention on the Rights of Persons with Disabilities Optional Protocol,

2016, p. 3) and individuals with disabilities are “now recognized under international law as rights holders with a claim to the right to education without discrimination and on the basis of equal opportunities” (p. 1).

Beliefs supersede policy when it comes to supporting oppressed people in education and most support movements are instigated by those who care (O'Donnell-Lussier & Shetron, 2018). While all the administrators in the study held similar beliefs in the growth and development potential of students with ID/DD and they all considered individuals with ID/DD to be examples of human variation rather than indicators of deficiency, one administrator, Lori, looked to the law to provide justification for PSE inclusion for students with ID/DD. While she did hold the same beliefs as the other administrators, her reference to policy demonstrates the strength policy can have in implementing inclusive practices. However, beliefs in the rights of all humans to have access to lifelong educational opportunities in socially valued locations instigated the movement, not policy. This is a situation that parallels other civil rights movements in which advocacy instigates policy, and then policy overcomes pushback from those who don't believe the same way.

Administrators beliefs also include supporting human growth and development for each individual regardless of measurements valued by society (i.e., successful degree attainment, high test scores, or IQ scores) and a consideration of equitable access to the same PSE environments and supports afforded all other matriculated college students informs their practices. Inclusive practices include creating matriculation codes which allow students with ID/DD to be registered in campus systems just like any other student. This coding helps remove barriers to accessing financial aid, campus housing, dining

services, sporting and other extracurricular activities that matriculated students have access to, it also provides them the opportunity to play on competitive sports teams when they are qualified to.

Person-centered program design, appropriate supports, and the opportunity to explore academic and vocational opportunities are all inclusive practices that align with services that regularly matriculated students are provided through advising and supports such as tutoring and writing centers, and other support practices such as learning communities. By providing these services in ways that are meaningful for their students, administrators demonstrate their belief in the growth and development of students with ID/DD and erase the division between their students and regularly matriculated students.

By providing these services, administrators also align themselves with the CRPD, which mandates that educators should “transform culture, policy, and practice in all formal and informal educational environments to accommodate the differing requirements and identities of individual students, together with a commitment to removing the barriers that impeded that possibility” (CRPD, 2016, p. 2-3).

Findings in the area of beliefs also align with studies on special education administrator beliefs in K–12 education that indicate K–12 administrators with prior experience with individuals with disabilities and who have knowledge of special education laws and practices are more likely to move beyond compliance and to support full inclusion of students with disabilities and to actively seek opportunities for students with disabilities to be included (Allan, 2016; Templeton, 2017; Vasquez, 2010). While their tasks are similar, administrators at the PSE level, however, demonstrate an increased advocacy role because the level of education they hope to provide and which they believe

students with ID/DD will benefit from are not mandated.

### **Knowledge of Oppressions**

*“Any situation in which “A” objectively exploits “B” or hinders his and her pursuit of self-affirmation as a responsible person is one of oppression.”*

(Freire, 1970/2013; p. 55)

Although the definition of ID/DD provided by the American Association of Intellectual and Developmental Disabilities (2018) states that ID/DD is a disability characterized by “significant limitations in both intellectual functioning and in adaptive behavior...” (n.p.), Freire asserts that “projecting an absolute ignorance onto others, a characteristic of the ideology of oppression, negates education and knowledge as processes of inquiry” (1970/2013, p. 72). Although limitations are listed as an integral part of an ID/DD diagnosis, administrators mentioned that many limitations are imposed on the student from outside and are not connected directly to the student’s ID/DD. These limitations included limited opportunities to develop intellectually in inclusive spaces and limited opportunities to learn about the world around them and to gain an understanding of all the possibilities from which they can chose to plan their lives. The administrators noted that lowered expectations focus on student deficits rather than on developing student strengths. Daphne, who attended special education classes in elementary school, described the curriculum as “dumbed-down” and saw a difference in the expectations placed on kids with ID/DD compared with those in the mainstream classes.

This finding is particularly salient because K–12 education is now mandated for students with disabilities, and the quality and content of this education serves as the preparation for students beyond the K–12 realm. As students with ID/DD are provided

access to the same postsecondary opportunities as students without ID/DD, the differences in their K–12 education experiences become more apparent, and deficits at this level may be attributed to prior educational experiences and are not necessarily a result of students’ diagnosis.

Freire notes that “one of the gravest obstacles to the achievement of liberation is that oppressive reality absorbs those within it and thereby acts to submerge human beings’ consciousness. Functionally, oppression is domesticating” (Freire, 1970/2013; p. 51). In this statement, Freire is pointing out that oppressive situations are superimposed on the consciousness of the individual subjected to them. Daphne’s experiences aligned with Freire’s observation. Daphne became aware of her own internalization of messages she’d received from the environment regarding her disability during a class that pointed this phenomenon out to her. She said; “that class challenged a lot of the things that were naturally thinking in my brain even though I didn’t necessarily sign up or subscribe to those thoughts: They just were.” Daphne realized she had thoughts that were put in her head from the environment and that did not originate from her own volition. She later commented that these still impacted her, particularly when she entered a room in her wheelchair and had thoughts such as “it’s so kind of you to let me take part in this meeting.” Daphne’s experience illustrates the internalization of external oppression.

### **Conscientization**

*I strongly believe that we, women and men, become able to interfere in the world which we did not make to the extent that we achieve consciousness of ourselves which in turn is acquired through consciousness of the world.*

(Freire et al., 2014, p. 42)

Although all nine administrators recognized many types of oppressions that students faced, and that students with ID/DD are frequently subjected to lower academic standards, social exclusion, marginalization, stigma and abuse (Ali et al., 2016; Koh, 2004) only the administrators who described experiencing conscientization, or some type of critical self-reflection mentioned altering their practices to accommodate students' inner psychological adjustments to the postsecondary environment. The administrators who had connections with disability, diversity, or some other stigmatizing or marginalizing experiences indicated an understanding that their students needed to work through psychological issues that might appear to be behavioral, non-adaptive, or stemming from ID/DD, but may, in fact, stem from being in a completely new environment that they had not previously experienced. Javier had suggested that many students with ID/DD had never even spent the night away from home and Lori mentioned that, at 26 years old, one young man's mother still put his clothes out for him every day. The only administrator who did not relate a story of conscientization or critical self-reflection attributed such behaviors that might be connected to internalization and psychological damage to a student's having a lack of self-confidence, or using their disability to get out of doing work (manipulative behavior) whereas the others commented that it becomes ingrained in the student's head that they aren't capable when they aren't offered the opportunity to try.

Many of the administrators talked about student's lives being *scripted* or *narrated* for them and noted that by targeting the development of student voice and self-understanding, students gained agency over their lives. This aligns with the importance of person-centered planning and the development of student voice and agency over their

lives beginning in transition (de Fur et al., 1996) and extending to the postsecondary level (Getzel & Thoma, 2008).

Administrator conscientization is important because those who understood students' internal struggles used this knowledge to provide more finely tuned support services including considering how safe their students felt in the program and focusing on training other campus staff and personnel to respond supportively to students with ID/DD on campus. They emphasized focusing on student strengths (Myers et al., 2015) and described trainings that might be developed to educate other campus staff and faculty taking into consideration student's slower processing skills (Kail, 2000), using plain language and clear rules (Karreman et al., 2007), and being more patient (Getzel, 2008). They also mentioned using universal design which can lower barriers for all students by creating easier to understand materials that have supports embedded within them (Barajas & Higbee, 2003; Higbee & Goff, 2008). Adjusting practices in this manner provides better access and allows students with ID/DD the extra space, time, and alternative means of expression which helps them grow rather than continuing practices that control their narrative. When campus staff or faculty say things such as, "come back with a staff person and then I can help you" they are indirectly sending the student the message that the student doesn't have the power or skills to self-advocate when, perhaps, they themselves have not learned the skills to support students with various needs. Other supportive practices included curriculum designed to promote deeper self-exploration and encouraging students to use their college experiences to explore many educational and employment opportunities rather than being locked into a choice made at the time of admission when they may have been more limited in self-expression.



Although this finding indicates that conscientization is an important element in shaping administrator practices, or, as Freire refers to it praxis, this study only suggests that this is the case. Lori, the one participant who did not indicate personal proximity to disability or other marginalizing factors also had professional and administrative roles that were different from other administrators in the study. Lori's primary professional experience was training special education teachers rather than having hands on work with students in special education, and she was also part of team of administrators building their program. As part of a team, her individual role was to find individuals to perform the more hands on tasks and to develop the program and curriculum rather than doing so herself.

Regarding culturally responsive practices, however, it should be noted that Lori referred to the young adults in the college program as "kids" and "kiddoes," language that may inadvertently perpetuate stereotypes rather than equalize the students' identity with other college age students. I considered that her language use may be more indicative of her age (she retired just after the study), however further exploration of the two other administrators in her age bracket demonstrated a more heightened awareness of the use of language for intentionally creating equitable opportunities by avoiding patronizing or infantilizing language. Javier, who was closest in age to Lori, had pursued extensive training in social justice and social role valorization and was very interdisciplinary, while Lori's education took place in a single discipline at a time that she explains was "before inclusion." Javier's education was also spurred on by questions raised during his intensive hands-on work with individuals with ID/DD whereas Lori described quickly going through three levels of education up to a Ph.D. in a fairly short

amount of time. Lori also emphasized that she did much teacher training and did not emphasize hands on experiences with the students.

Lori's interview revealed a major limitation of the study's design which was the need to conduct additional studies until saturation is reached. Her responses revealed new avenues that need to be explored and her responses were so different from the other responses that even my probing questions did not seem adequate to get the type of information that surfaced freely in the other participant's interview. Lori's case prompted a heightened examination of participant age, background education, exposure to social justice and critical education topics, and the contribution to practice that personal experiences with marginalization may have.

### **Critical Lens and Language**

*"Solidarity goes side by side with a critical mind"*

(Freire et al., 2014, p. 43).

A final theme that arose was administrators' use of critical language. A primary goal of critical thinking is to be able to announce and denounce injustices which, in turn, may lead to a disruption of the status quo. By having the ability to label things as biases, prejudices, limiting, unfair, unjust, or inequitable, the administrators who employed a critical language were able to address root causes of problems rather than consider barriers as being localized or limited to individual circumstances. By critically problematizing barriers, these administrators looked to principles such as humanization and moral responsibility towards others as their guiding principles rather than chipping away at barriers to eke out a place for a program on their individual campus. Focusing on the critical elements to establishing programs can help prevent a reproduction of the

status quo, which in this case, might look like the recreation of special education services at the college level; the opposite of the movement's humanizing roots and intention for inclusion.

This finding is important because administrators are in positions that can effect change on campuses that benefit both the campus and students with ID/DD. As the recent research on program implementation suggests, forming partnerships, establishing implementation committees, and working with both on-campus personnel and departments and community partners and families is a key part of the administrator role, but, as Kavulic (2017) noted, personal stories that generate interest may not keep a program together unless it becomes embedded into the fabric of the institution, something which Daphne noted had happened at her institution stating that the program had become part of her institution's identity.

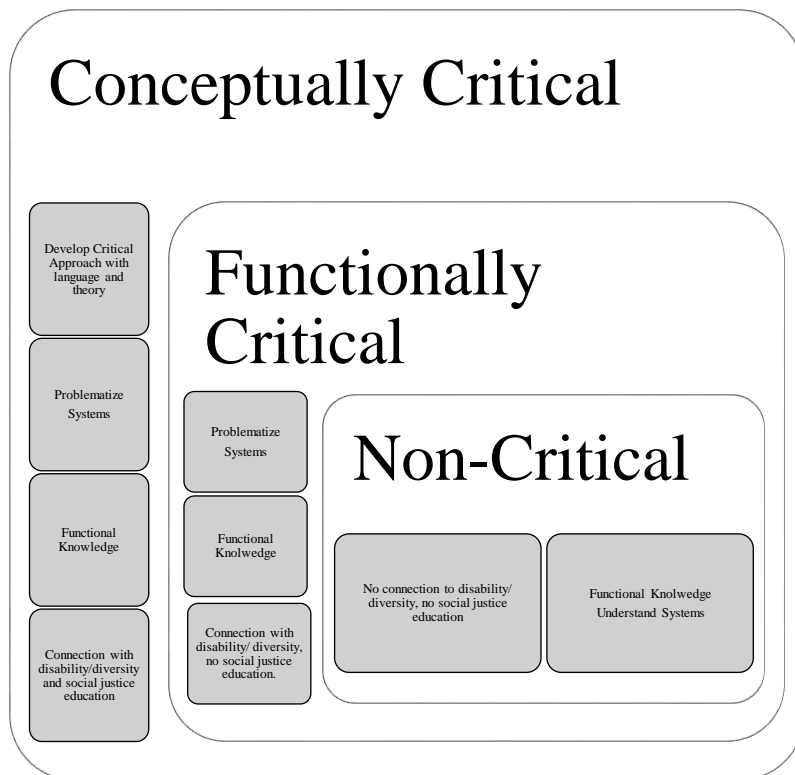
Recent literature on program development focuses on external structures of program development (Baker et al., 2018; Francis et al., 2018) rather than practitioner knowledge and how their knowledge might influence the implementation of the structures which they suggest. While forming committees and relationships with various constituents is one of the most crucial tasks of the administrator, there is no literature at the postsecondary level discussing how administrators might navigate the social, cultural, or political climate at their campus or where they might turn to gain this type of knowledge.

Freire emphasized the importance of creating an ideological map of the institution in which one is hoping to start work that creates a critical change. He explains; "I need to know who I can count on, with whom I am alike, and against whom I may have to be. If I

don't know the levels of power of those opposite me, I cannot fight." All the administrators in the study described establishing relationships with campus and community groups. Many of the conversations started between the administrators and others with whom they shared ideological values. Emilia said her program started over dinner with a colleague and the initial plan was written on a napkin, almost all the other programs began as a result of conversations that had already been established between transition units in local school districts and community providers and community members. Administrators who were already part of these groups had an established ideological agreement with these groups. When it came time to making inroads on campuses however, most of the administrators noted that they had to find advocates and people in power who would be their *champions*. Javier had mentioned having a friend in the president, and Ethel had mentioned that her champion her program overcame some pushback because their campus champion had more power than the opposing group. helped her program successfully overcome some push back because her champion had more power.

Findings from the study indicate the importance of administrators building upon their functional awareness of the needs of students with ID/DD by engaging in deep, critical self-reflection and taking courses in social justice or critical theory (see figure 3). Developing a critical awareness can help administrators better identify with students and provide more fine-tuned supports including space for their psychological adjustment to being a college student. Critical studies also develop a critical lens for examining surrounding systems to identify and address barriers to inclusion. Critical studies also help develop a language that might provide a needed unity of terminology in the field that

makes clear that students with ID/DD face many inequities. Providing this language for administrators is the first step in helping them to provide their students with the same language, further developing their development as self-directed citizens.



**Figure 3**  
*Comparison of Different Types of Critical Approach*

### **Limitations and Delimitations**

Limitations in this study included time and funding limitations preventing research from being conducted face to face and utilizing campus visits to provide additional supporting documents and observations. A lack of prior research which served as the impetus for the research also left the exploration wide open with minimal guidance or examples from tangential areas in higher education. During the research process, the

value of data saturation became more apparent, but was unattainable given the study design and the limitations listed above.

Delimitations were set when I stopped pursuing information from my participants and chose to write up findings as they currently existed at the time, although additional questions for further probing existed. I addressed this delimitation by offering my focus cases a final opportunity to assess my summaries of their experiences, and given their consent, after receiving their feedback, I stopped collecting data and proceeded with analysis and writing final reports.

### **Implications**

Findings from the study indicate that inclusive PSE practices can come from specialized knowledge of students with ID/DD that can be gained in four ways; (a) from educational experiences, (b) from professional experiences, (c) from personal experiences, and (d) from varying combinations of these experiences, and that beliefs serve as a pervasive foundational attitude for administrators and may also be derived from experiences through gaining knowledge of student capabilities and shifting perspectives from deficit approaches to strengths based approaches. While experiences of all types can occur in formal or non-formal settings, one educational process; conscientization, has the capacity to help administrators inventory their own personal, professional, and education experiences and critically assess them by considering their own experiences in relationship to surrounding social, political, economic, and historical systems. This critical self-reflection helps them consider their own experiences in relationship to their students and determine how alike or non-alike they are with their students and to tap into personal experiences when considering best practices for

implementing inclusive PSE. My implications, therefore, focus not on types of experiences (i.e., personal, professional, and educational), but on broader categories of “education,” “conscientization,” and “beliefs,” connecting these to my findings and the literature. Further implications are centered around the use of other theoretical frameworks for data analysis.

## **Education**

Only two administrators, Emilia and Lori, had three degrees in special education (BA, MS, and Ph.D.). Lori adamantly credited her degrees with providing her with the credentials for being qualified to work in special education. Emilia, on the other hand, also had three degrees in special education and lamented that these degrees did not provide her with the social justice language and understanding she needed to really do the deep work of understanding the injustices that students with ID/DD face. When pressed to discuss her thoughts on educational fairness for students with disabilities, Lori discussed law and policy and stated “it was really important for me and for my overall professional development to learn all those things...the deal is, when you know those things, then all of a sudden it’s kind of like, hey, I don’t see that happening...it we’re talking about inclusion in K–12, why isn’t it inclusion in higher ed?”

Emilia, on the other hand, lamented that her entire formal education in special education provided her with no social justice knowledge and she had to seek the thing that she innately felt was crucial to the topic on her own. Emilia prompted educators to always be self-reflective and ask themselves “why we’re doing the work we’re doing” and she credited her growing social justice and educational equity awareness with seeking this knowledge on her own and forging relationships with others on campus who

were experts in this area and could help her understand the things she saw and felt, but didn't yet have a language for. Javier and Ethel, like Emilia, pursued education in social justice from an inner drive to understand what made them uncomfortable about the injustices they were viewing—Javier from the injustices he saw in the lives of people with ID/DD, and Ethel from both her own experiences and the injustices she witnessed in the lives of people with ID/DD.

Education, therefore, does, as the research on K–12 administrators indicates, (Templeton, 2017) impact educator knowledge and ability to facilitate inclusive PSE. Education focusing on social justice and educational equity, however, is needed to help administrators understand and label the pervasive inequities that people with ID/DD experience and to address these through their educational practices. Freire's work hinges on educators having a firm grasp of the relationships between the people they educate and surrounding social, economic, and political systems. Emilia, Javier, and Ethel realized that they could not do their work without this knowledge and pursued it either through independent study, professional development, or, in Ethel's case, formal degrees in cultural foundations of education. Lori's work was, indeed propelled by the knowledge she gained in school about the surrounding political systems (i.e. disability policy).

Several implications regarding the topic of education are applicable not only for the emerging field of inclusive PSE but are also applicable for graduate programs and teacher training in developmental education as well as other education leadership training. The first focuses on including disability studies and disability education policy in education policy courses. Failure to include these topics in all education classes further marginalizes individuals with disabilities contributing to an out of sight-out of mind



mentality. In addition to including policies specific to people with disabilities, education preparation programs (special education, developmental education, and education leadership programs) should include courses on social justice and educational equity which serve to illuminate pervasive injustices that individuals with physical and intellectual disabilities faced alongside other marginalized populations and can help educators develop a critical stance as well as a critical vocabulary with which to discuss witnessed injustices. Further implications for the field of DE, which already engages in research on marginalized student populations includes adding research on students with ID/DD to the body of student populations currently being studied, although caution should be exercised as the student body is small and vulnerable and should not be subjected to research fatigue. A good beginning would be incorporating descriptions of this student body into the DE literature to help educators gain awareness of this population that is growing and attending DE courses (Sue Moraska, personal communication, September 2017). The next section focuses on a sub-component of social justice education; conscientization.

### **Conscientization**

Conscientization is a type of education that focuses on inward self-reflection and can be undertaken through formal education or independently. Conscientization is the process of examining multiple aspects of one's life (i.e., sex, gender, economic status, race, religion, or any other diversity or minority status) and locating one's relationship to systems of power and privilege that might be associated with these different categories. The end result is to become critically self-aware (Freire, 1970/2013). Freire equates our consciousness of ourselves with our consciousness of the world.

As noted in the findings, Lori was the only administrator who did not refer to any type of critical self-awareness. She was aware that her natural disposition was a good match for her work in the field of special education teacher preparation, but she made no mention of her relationship to sex, gender, economic status, race, religion, or any other diversity or minority status. Of the other eight who did make mention of these, three (Javier, Emilia, and Ethel) sought additional opportunities to better understand themselves and their relationship to systems of oppression through additional formal and informal instruction. One, Daphne, specifically mentioned learning about her own internalized oppression during a disability studies class, but this knowledge was isolated from practicing critical-self-reflection in other areas.

In addition to these four administrators mentioned already, there was a notable difference in the how critical self-awareness was displayed with a distinctive age and discipline divide. Rachelle and Bobbie, both in their 30s were at ease talking about their personal situations barely acknowledging that they were talking about critical self-awareness. Rachelle noted that in the field of social work, social justice is “everywhere” making the connection between social justice education and social justice awareness, Bobbie had practiced much critical self-reflection on her own and in counseling. Neither connected their experiences with their work until I asked them specifically about it. Jane and Maggie, at the other end of the age spectrum in their 50s, not only articulated their awareness of the injustices they’d faced based on things they encountered but made direct connections to their practices as a result of those experiences. However, neither Jane nor Maggie considered themselves as marginalized or diverse even though they talked about their marginalizing experiences and diversities.

Implications for the fields inclusive PSE and DE are that programs aimed at developing educators who work with students with ID/DD should have a component that prompts educators to critically self-reflect. In my own developmental education program, critical self-reflection was a core component in my multicultural and diversity studies. I was through critical self-reflection that I came to understand my interest in this topic and the impact that my own experiences with disability had on my knowledge in supporting students with disabilities. More specifically, training in how to incorporate critical self-reflection into course work (Mezirow, 2003) would be valuable at practitioner conferences for both inclusive PSE and DE personnel. Finally, an additional benefit of teachers who are trained to become critically self-aware is that they then have the ability to help their students become critically self-aware which is a first step towards understanding self and circumstances and gaining voice and agency. In the realm of disability, terminology for voice and agency would be self-determination, self-advocacy, and person-centered planning.

### **Beliefs**

All nine administrators demonstrated beliefs in the growth and development potential of students with ID/DD as well as the location of individuals with ID/DD within the full spectrum of humanity. This also aligns with the research on K–12 administrators which generally connects the source of beliefs to prior experiences, but also connects beliefs to the provision of inclusive practices (Allan, 2016; Praisner, 2003). As noted, students with ID/DD have strengths and weaknesses just like everyone else and labelling and diagnosis are not precise (Harrison & Holmes, 2013; Schalock et al., 2007; Quick et al., 2003), but there are a certain group of distinctions that can be generally applied which

can help support effective educational practices (Field et al., 2003; Getzel, 2008; Kail, 2000). Educators of students with ID/DD who believe in their growth and development potential have somehow overridden societal generalizations about individuals with ID/DD, or, as Emilia stated “the most difficult things are the barriers set in place by society...many people within society view them as ‘they cannot do things’ so, they cannot grow.” Lori, too, was adamant that busting stereotypes was crucial to moving inclusion forward.

The collective findings on beliefs help push the movement into the human rights arena where it belongs. While Freire insisted that a denial of education to any individual constituted oppression, the CRPD (2016) codifies this sentiment into policy stating that access to education for every human is a fundamental right, and that individuals with disabilities are recognized under the law as “rights holders with a claim to the right to education without discrimination and on the basis of equal opportunities” (CRPD, 2016, p. 1). Unfortunately, although the CRPD was adopted by the United Nations in 2006, and entered into force in 2008, the United States is not one of the 177 countries to ratify the CRPD human rights treaty (Kanter, 2019).

Implications regarding administrator beliefs are that, in the process of promoting critical self-reflection, the distinction between knowledge and attitudes should be made. Practitioners may find that, like Lori, their knowledge doesn’t completely align with their attitude. Lori knew individuals with ID/DD can grow and change, but she still referred to them as “kiddoes.” and seemed surprised when teachers were enthusiastic about their students coming to college. Freire noted that even helpful systems can inadvertently maintain oppressive situations, a situation which both Jane and Javier alluded to when

they pointed out inequities that were perpetuated in vocational rehabilitation jobs. Jane was told she was causing trouble when she asked her students what they thought about doing the repetitive silverware sorting job, and Javier was also dissuaded from helping his students find jobs—without a room full of individuals needing jobs, job placement services might become unnecessary and receive funding. By helping educators understand their underlying beliefs, they might be able to better clarify how to react in difficult situations in which they are called upon to advocate for their students, even referring to human rights laws for support.

In summary, administrators may participate in many types of education; formal, informal, critical, non-critical. Critical studies can expand administrators' awareness of underlying systemic causes of oppressions with students with ID/DD. Conscientization, a component of critical studies can help administrators connect their own circumstances to the same underlying systemic causes of oppression that their students experience which can help administrators' adjust their practices to create programming and support practices focused on meeting the underlying sources of student characteristics or responses to the college experience. Beliefs, unlike knowledge, can also be developed through critical self-reflection, and, when tied to practices, can develop clear guidance for educator practices. Javier summarized this; (1) how is it that good people can do harmful things in the name of good? And (2) what can I do about it?

### **Other Theoretical Frameworks**

My use of Freire's educational philosophy represented just one way in which critical theory could serve as an analytical tool to explore the data. While particularly relevant and useful in this research context because his educational philosophies are

widely transferable to other settings and focus on a belief that education is a humanizing process, a particularly heuristic approach when considering a population that has been denied basic human rights and considered, denied basic human rights, and are highly stigmatized, marginalized, and subject to abuse (Ali et al., 2016; Butler et al., 2016; Ditchman et al., 2013; Fisher et al., 2013; Hall, 2005; Koh, 2004). Focusing on humanizing practices highlights the need to consider the basic humanity and human rights of the individual being educated connecting the topic to conversations regarding the purpose of education and who should have access to it (Sleeter, 2012), and how we should measure educational growth and content (Alexander, 2010; Noddings, 2015).

Based upon the finding that critical language was useful in identifying and discussing injustices, and the enmeshed connections between administrators personal, professional, and educational experiences contributed to their development of knowledge, critical discourse analysis could lead to deeper findings and bring out other aspects of administrators' experiences that the use of Freire alone did not. Other possible theories for analysis include Noddings ethics of care and education based in a philosophy that care is a basic part of the human experience (Noddings, 2002) or social justice education leadership (Theoharis, 2007) which examines how educational leaders enact social justice, react to resistance, and enact strategies to sustain their social justice work in their institutions.

### **Recommendations for Further Study**

A next logical step in this research trajectory would also be gathering administrators together in participatory action research. Their collective knowledge and experiences add more to the topic than that of any single practitioner, and a purposeful

sharing of these could provide a useful addition to the more segregated, program focused accounts currently available. Expanding groups to include students and inviting students into the research would also increase student voice and agency, a main purpose for the programs. Participatory action research that invites students with ID/DD into the research process is considered the most liberating form of research for them and provides them a platform to speak their own truth (Ryan et al., 2015). It should, however, be considered that student numbers in ID/DD programs are not large; approximately 10 per class year per institution, and specifically targeting these students may cause fatigue or produce undue burdens.

Such collaborative efforts could (a) help form a unified language for addressing the inequities and barriers that administrators encounter as they develop programs that utilize campus and community resources, (b) move these discussions beyond personal stories of loved ones with disabilities to a higher, theoretical and critical level, and (c) place the students and human rights at the center of the conversation considering structures and systems as a means for supporting human rights rather than, as Ethel stated, coming with hat in hand, to beg for handouts.

According to Bumble, et al., 2019 and Francis et al., 2018, conversations and establishing relationships with multiple vested parties are at the center of program development and implementation. Bumble et al. specifically noted the value of different types of inputs and information that a wide variety of stakeholders bring to the table when discussing inclusive PSE. Kavulic's (2017) findings emphasized the value of developing personal, emotional stories, and purposefully increasing the amount of story sharing in order to gain institutional buy-in. My recommendation is to harness the power

of all these stories through theorization where they can be employed in theoretical and practical discussions in multiple areas (e.g., disability studies in higher education, developmental education, and critical and cultural studies in education). Freire recognized the relationship between schools and communities and said they must be “anchored in relationships of solidarity” (Darder, 2011, p. 188), theory building can provide that anchor.

Additional research could also be conducted exploring administrator’ qualifications and prior experiences and how qualifications and experiences impact their inclusive practices. The design of this study is replicable and future studies on administrators that allow for data saturation may lead to the development of grounded theories from which a practitioner knowledge base can be derived leading to further professionalization of the field of inclusive PSE for students with ID/DD. Additionally, further examinations of administrator practices, particularly those derived from their critical knowledge of student oppressions, may serve as a foundation to develop culturally responsive educator and leadership practices for those facilitating inclusive PSE is suggested (Khalifa et al., 2016; Ladson-Billings, 2014).

Finally, the fields of inclusive PSE and DE should consider working together when conducting studies on students in DE classes or college students in general to make sure that all college students are included in such studies. Perhaps, through such studies, teaching pedagogies and inclusive practices will be implemented that bring greater ease of accessibility to more students just as the principles of Universal Design has done.



## **Conclusion**

Inclusive postsecondary education for students with intellectual and developmental disability introduces a novel student population to college campuses whose presence on campus emphasizes the civic and social purposes of higher education as well as the benefits of accessing lifelong education in socially valued places and the human right to such access. As a novel area, research, practice, and policies are evolving concurrently and the need is great for knowledgeable practitioners to share what they have learned to influence this concurrent growth. This study emphasized taking a critical stance to inclusive PSE by focusing on the source of the knowledge that administrators bring to their work and how this knowledge can impact their practices.

Findings indicated that administrators' beliefs regarding the humanity of students with ID/DD, their knowledge of oppressive situations students with ID/DD face, their critical-self-awareness which prompted solidarity with students, and their development of a critical language all contributed to their conceptualization of inclusive PSE for students with ID/DD, particularly in recognizing injustices that prevent equitable access to inclusion and prevent students from growing and developing like other college students.

## **Chapter Summary**

In this final chapter, I interpreted the major findings of the study by focusing on the collaborative development of administrator beliefs and their knowledge of student oppressions. By establishing beliefs as foundational to practices, superseding policy support. Beliefs tie the inclusive movement back to its humanizing roots. In considering the foundation of Freire's educational philosophy, humanization, and considering that he holds all humans accountable for dehumanizing practices, this

elevates the discussion of inclusive PSE to the level of general social responsibility for supporting human rights. In focusing on administrator's knowledge of student oppressions, both internal and external, I posit that these novel administrators are in a position to address these oppressions through their educational practices and to enlighten others regarding the limitations that such oppressions place upon the growth and development of students with ID/DD.

Furthermore, *conscientization*, was put forth as a key component which helps administrators connect their personal experiences to their student's experiences fostering a deeper solidarity with their students, including an understanding of the psychological development students go through when they come to college. While most administrators were prompted by their own stigmatizing and marginalized experiences such as having a disability or some other diversity status (i.e., minority, low socio-economic status) to engage in critical thinking, the process of critical self-reflection produced the solidarity and not the type of experience being reflected, although the type of experience helped provide guidance for specific practices, underscoring the value of collaboration amongst administrators for developing programs (Darling-Hammond, 2016).

In addition to conscientization, my findings indicated that administrators who also pursued education in social justice studies or critical studies, developed a critical lens from which to examine the oppressions they and their students faced and supported the development of a critical language from which to draw in order to discuss these oppressions, or inequities. The value of a critical language being that it cuts through surface barriers to deeper underlying ideologies and can elevate the conversation from a localized situation to one of human rights and civic and social responsibility.

I concluded the chapter by making clear the limitations and delimitations of the study, providing implications for the fields of inclusive PSE and DE, and providing recommendations for further study primarily focusing on replication and expansion in order to generate theory and support the further professionalization of the administrator role. Finally, this critical exploration of the personal, professional, and educational experiences of administrators of inclusive PSE probed the heart of the movement, providing humanizing experiences and opportunities for people with ID/DD, a basic human right that we all are responsible for.

## APPENDIX SECTION

### Appendix A

#### Sample Program Information

Sample A, 4-year program plan

Course No. Short Title

Course No. Short Title

#### CORE PROGRAM 1 (18 credits)

##### Social Work

SOWK 102 Modern Social Welfare Dilemmas (G3)

SOWK 201 Social Welfare Policy & Econ

SOWK 303 Social Welfare and the Law

SOWK 323 Human Behavior & the Social Environment I

SOWK 350 Encounters in Human Diversity (D, P)

##### Choose 1

SOWK 304 SW, Corrections & Alt, Treatment Approaches (G3)

SOWK 305 Social Work and Child Welfare

SOWK 306 Social Work and Aging

SOWK 307 Social Work and Healthcare

SOWK 308 Social Work and Alcoholism

SOWK 309 Social Work & Mental Health

SOWK 312 SW&Women: Strengths, Needs, Opportunities (W, G3)

SOWK 313 Family Violence (P)

SOWK 314 Global Well-Being (D, P)

SOWK 315 Grief and Bereavement in a Diverse World (D)

SOWK 316 Mediation (G3)

SOWK 475 Special Topics in Social Work

COMM 201 Theory of Communication

#### CORE PROGRAM 2 (18 CREDITS)

WSTU 220\_Introduction to Women's Studies

WSTU 330\_Feminist Theory

WSTU 345\_Feminist Research Methods

#### REQUIRED RELATED (9 credits)

##### Co-op Experiences

\_\_On Campus INTERNSHIP #1\_\_

\_\_On Campus INTERNSHIP #2\_\_

\_\_Off campus INTERNSHIP #3\_\_

#### GENERAL ELECTIVES -

##### RECOMMENDED

MATH 070

EDFN 090

UNIV 103

ENGL 110

COMM 100

WELL 175

##### - GUIDELINES

> Capstone Course The capstone experience (3 credits) is an advanced course, internship, practicum, apprenticeship, individualized instruction, or applied research seminar that challenges students to integrate knowledge across more than one discipline, to engage in vocational practice or experiential learning, and develop applied life and vocational competencies. The capstone course may apply to any of experience will be offered under faculty direction and will

Choose three:

ANTH 322	ENGL 429
Food and Culture (G3, W)	Seminar: Black Women Writers
ANTH 344	ENGL 435
Gender, Race and Class (P)	Journalism Through Women's Perspectives
BUAD 405	GOVT 408
Topics: Gender and Diversity	Seminar: Women in Global Politics
COMM 330	HIST 210
Media and Women's Culture (P)	Women in Western Civilization (G3, W)
COMM 333	HIST 250
Gender and Communication (D)	33, W)
ECON 327	NURS 316
Women and Global Economic Development (P)	Women, Health and Healthcare (P)
EDFN 312	PHIL 391
Women and Education:	Gender, Utopia and Human Behavior (P)
Socialization and Liberation (P)	SOCY 329
EDFN 376	Topics: Feminist Theory
Whose School Is It, Anyway? (D, P)	SOCY 339
EDUC 433	Topics: Gender and the Law
Gender and Race Issues in Children's Literature (P)	SOWK 312
ENGL 331	Social Work and Women's Issues (G3, W)
	SOWK 313
	Family Violence (P)
	SSCI 212
	The Black Woman (G3)

the core programs or a combination. The capstone

be purposeful in connecting students' academic learning to their future career and professional goals as detailed in the transition plan.

> Each Core Program is identified as developing the student's primary transitional career & life goals. Each core program is based on a match between the student's goals / interests and minors or modified majors offered to MU students.

> Person-Centered Planning is a set of tools that each student engages in as a prerequisite to program admission. The goal of the planning process is to determine initial course program individualized for the student. This may be submitted to Institution prior to submission.

Involvement of university staff is suggested.

Any alteration or exception to the IS curriculum must be approved by both the faculty advisors and by the INST Director

> **The Core One Program** is identified as the student's primary program, and includes at least three advanced courses.

> **The Core Two Program** includes at least two advanced courses. While the individualized courses selected might also meet the requirements of the general education requirement in the existing

Topics: American  
Women Writers  
ENGL 337  
Women Writers in the  
Middle Ages (P)  
ENGL 416  
The Woman Writer  
and Her World

**Note to the Student**

This form is provided as a guide. It is your responsibility to consult regularly with your advisor to be aware of changes and curriculum details which are not incorporated on this form.

> Note: With the approval of the Program Director and the student's advisor(s), the individualized Core Programs may be modified to include approved internships, independent studies, apprenticeships or individualized instructions.

The core programs may also comprise modified existing MU majors.

This is a transitional person-centered course of study.

Programs are designed in conjunction with the student, district, LEA, family, Supports Coordinator and program staff.

University curriculum. Any alteration or exception to the IS curriculum must be approved by both the faculty advisors and by the IS Director.

## Sample B: Eight-Semester Plan

### Fall Semester — Year 1

- EMPR 1003 — Seminar
- UNIV 1001 — University Perspectives
- PBHL 1103 — Personal Health and Safety
- COMM 1023 — Communication in a Diverse World
- Electives — 5 hours of EMPOWER or regular courses; may include Physical Education Activity/ Recreation/Fitness classes

### Spring Semester — Year 1

- EMPR 1003 — Seminar
- HESC 1403 — Life Span Development
- COMM 1313 — Public Speaking
- Electives — 6 hours of EMPOWER or regular courses; may include PE Activity/Recreation/Fitness classes

### Fall Semester — Year 2

- EMPR 1003 — Seminar
- NUTR 1213 — Fundamentals of Nutrition
- Electives — 9 hours of EMPOWER or regular courses; may include PE Activity/ Recreation/Fitness classes

### Spring Semester — Year 2

- EMPR 1003 — Seminar
- UNIV 1401 — Career Exploration
- EMPR 2013 — On-Campus Internship
- Electives — 8 hours of EMPOWER or regular courses; may include PE Activity/ Recreation/Fitness classes

### Fall Semester — Year 3

- EMPR 1003 — Seminar
- EMPR 3016 — On-Campus Internship
- Electives — 6 hours of EMPOWER or regular courses; may include PE Activity/ Recreation/Fitness classes

### Spring Semester — Year 3

- EMPR 1003 — Seminar
- EMPR 3016 — On-Campus Internship

- Electives — 6 hours of EMPOWER or regular courses; may include PE Activity/Recreation/Fitness classes

Fall Semester — Year 4

- EMPR 1003 — Seminar
- EMPR 4129 — Off-Campus Internship
- Electives — 3 hours of EMPOWER or regular courses; may include PE Activity/Recreation/Fitness classes

Spring Semester — Year 4

- EMPR 1003 — Seminar
- EMPR 4129 — Off-Campus Internship
- Electives — 3 hours of EMPOWER or regular courses; may include PE Activity/Recreation/Fitness classes



## **Appendix B**

### **Additional Participant Synopses**

#### **Daphne**

Daphne is a woman in her early 40s who was instrumental in the design and implementation of the inclusive program at her 2-year community college which began accepting students in 2016. Daphne has been at her institution for over 13 years and she currently holds a dual role as Associate Professor-Disability Learning Specialist and as the program administrator for the inclusive PSE on her campus. Daphne has a Bachelor's degree in Rehabilitation Services and a Master's degree in Counselor Education with an emphasis on Rehabilitation Counseling. Prior to her current position she held positions as a Disability Learning Specialist and an Assistive Technology Coordinator at other institutions of higher education. She has also been a practicing rehabilitation therapist.

Daphne was born with Cerebral Palsy and her entire life has been spent around individuals with disabilities. Although she didn't have a cognitive disability, she was placed in special education during her elementary school years and participated in Special Olympics. Daphne credits her personal experiences "living the life, day to day" as the focal point of her training in the field.

I know I'm only one individual with one perspective and one set of experiences, but, I do think that that level of interaction with the world helps give you a unique training to prepare you in how you might assist others in going through that journey.

Daphne uses a power wheelchair for mobility, and her main contributions to her program's design and implementation include her awareness of students who could

benefit from additional supports, her ability to coalesce multiple stakeholders to generate interest, ideas, and funding, and her in-depth, personal understanding of the barriers and limitations individuals with disabilities face, including the internalization of their disability. Daphne's experiences prompted her to design a program that (1) provides multiple types of certificates that allow for different and flexible levels of supports to accommodate a broad range of student diversity and ability while still being inclusive, (2) part of her program design included creating an "advisory" team to look at the big picture and examine the program's mission and vision and help them stay true to their inclusive goals as well as an "implementation team" which anticipated the need to educate the rest of the campus about students with ID/DD to support full campus inclusion, and last, (3) her personal experiences with disability developed a comprehensive understanding of oppressive practices and structures that individuals with disabilities including internalization of limitations, fear of the unknown, and lack of prior experiences including lowered expectations which prevent the development of self-advocacy and other age-appropriate behaviors.

Daphne's role and her program are unique in two primary ways. First, her program is the only program that is seated in the Office of Disability Services (ODS) on her campus, and second, her program is the only program run by an individual who has experienced life with a disability and who also experienced special education. Daphne spoke about dehumanizing practices that become limiting factors in student's growth and development. Daphne's advocacy and knowledge stem from a solidarity developed through lived experiences.

## **Ethel**

Ethel is a woman in her 40s who was hired by the program at her 4-year public institution the year it was implemented (2007). She has a bachelor's degree in Psychology, a master's degree in Journalism and Mass Communications, and her Ph.D. is in Cultural Foundations of Education. She has 25 years of experience working with children and young adults with ID/DD in a variety of capacities and came to the work "tangentially" when she was introduced to this population during summer employment when she was in college.

Ethel was originally hired to be the program coordinator, but her position has changed over the years. Currently she is in charge of curriculum design and instruction. In this role, Ethel seeks to develop methods for helping students gain voice and agency using nontraditional methods, particularly artistic and creative expression including poetry and theater. Ethel pursued her Ph.D. while employed in this position and her dissertation focused on using arts-based methodologies and community engaged research with students with ID/DD. Her work seeks to understand how students consider their own growth in college and what supports they perceive are needed to achieve their desired goals. Ethel's primary goals are to help students gain voice and agency.

Ethel reported personal connection to disability in her family and personally. Ethel also identifies as a biracial woman. Ethel's educational pursuits are centered on identity work, social justice and educational equity and her knowledge in these areas serve as a foundation for her work with students with ID/DD. She firmly believes that to create a program that is both accessible and equitable, students should not have to prove they are different to get the support they need, and that education should serve as a means

for helping students develop a sense of self as well as provide access to learning about the world and the many options and possibilities for being that exist in it. Ethel's advocacy stems from lived experiences of intersectionality and social justice studies.

### **Lori**

Lori is a woman in her 50s who was instrumental in the design and implementation of the inclusive program at her public 4-year institution which began accepting students in January of 2016. Conversations to begin a program started in 2007 and were initiated by a local school district transition coordinator. Lori has three special education degrees (bachelor's, master's and Ph.D).

Lori reported that she had no personal proximity to disability or diversity. She became interested in working with people with disabilities through a volunteer opportunity she had in high school doing crafts in an afterschool program with transition age individuals with ID/DD. She has over thirty years of experience in special education at multiple levels and just retired from a tenure-track position after 23 years teaching and supervising special education majors. She frequently mentioned that she felt lucky to have fallen into a career she loved. She mentioned that the work was exciting and kept her from being bored, and that after her initial experience as a volunteer she thought "this would be like the bomb job." She emphasized the many different aspects of special education she'd encountered throughout her education and career including taking a welding class to learn how to put the training into language that would be understood by students with ID/DD, working at summer camps where she was promoted because she had special education credentials, and supervising student teachers including helping

student teachers with disabilities navigate their disabilities to become successful classroom teachers.

Lori was very knowledgeable and passionate about her job, and while she understood many of the barriers to inclusive education, she attributed ideologies supporting the inclusive movement to established laws and growth of the inclusive movement to newly established laws. Lori had a thorough conceptualization of all aspects of the special education system, however she did not indicate that she approached her practices considering that there were student needs that are not being addressed by policies or current practices.

### **Maggie**

Maggie is a woman in her 60s. The program at her 2-year, public campus began in 2010 and she replaced the woman who designed and implemented the program (date?). She came to the field of disability support later in life after third child was born medically fragile and was later diagnosed with autism and ID/DD. Maggie left a successful career as a consultant for major corporations where she used applied psychology and anthropology to design better work spaces for employees. Her bachelor's degree is in psychology and she has a master's degree in human factors, a type of applied psychology used for design and analysis. When her daughter grew up, she decided to use the knowledge she'd gained advocating for her daughter throughout her K–12 and postsecondary education journey and she went back to school to get an associate's degree in disability support. While she was obtaining her associates degree, one of her disability studies professors helped design and implement the program on her campus, and when

the professor moved on to something else, she contacted Maggie as a good replacement to administer the program.

Maggie's program is a bit different from most of the others because it consists of both a high school transition component and a community vocational support program and the two programs are run by two different staff and serve two different purposes. Her role includes intense coordination between the different partners, the college, and community employment internships. She does a lot of behind the scenes work coordinating space, courses, and internships. Maggie's favorite thing about her job is getting to know the students even though she realizes that they have no idea how much work she does behind the scenes to help them get the classes, social, and employment opportunities they want.

Like Daphne, Maggie has firsthand knowledge of what individuals with disabilities go through including being isolated "their special education classroom was down a few steps, in the basement, back some dark hallway where they didn't really interact with other students." Maggie experienced the impact inclusive education had on both her and her daughter when she enrolled in a high school for students with different abilities. "She finally got to do the things that she had always wanted to do. She blossomed. She became a person that was always there but could never come out because nobody would let her. It just changed her. She went from being depressed to being happy."

### **Emilia**

Emilia is a woman in her mid-30s who was born in Mexico. She came to the U.S. with her family when she was in middle school. She was instrumental in designing and

implementing the inclusive PSE on her four-year campus which opened in 2018.

Planning for the program began in 2015 with a new colleague who had come from an institution that had an inclusive PSE on it, and, coincidentally she was advising a doctoral student doing research on inclusive PSEs at the same time. Emilia switched her major several times before finding her calling in special education. She began her college studies in international business, switched to journalism and marketing, and then, after coming into contact with individuals with ID/DD through a volunteer position at a therapeutic riding center, she “fell in love with working with this population.”

Emilia holds three degrees in special education and has experiences working with students with intellectual disabilities in U.S. schools and in Mexico and Ecuador. She teaches courses in Diversity in Special Education, Research in Special Education, Curriculum and Assessment in Special Education, and Teaching in Inclusive Classes and her research focuses on addressing disproportionality in special education through culturally responsive practices and pedagogies. Emilia also has experience teaching bilingual special education.

Emilia has a personal connection to disability. She had a cousin who developed ID/DD after a series of seizures and her mother became very involved in helping the parents of the child figure out how to get medical care. Emilia also experienced middle and high school as an English Language Learner and recalls making the effort to eat lunch with kids with ID/DD because they were separated from all the other kids at lunch “because they take a little bit longer.” Emilia noted that in Mexico, individuals with disabilities are socially accepted and woven into community life, whereas in America, they are often found in the margins and excluded.

Emilia noted that during her three degrees in special education, she did not learn social justice or educational equity language, and that she pursued an understanding of these outside of her studies. Emilia credited her colleagues at her current institution with helping her develop a critical understanding of how both equity and access play a role in taking a social justice approach. “I’m finally getting that foundation and the language that I’ve been probably looking for the past 15 years.” She also noted the importance of addressing not just access, but equity in building programs, and noted that two of their five new students for their second year of operation are students of color.

### **Jane**

Jane is a woman in her early 50s. She was instrumental in the design and implementation of the inclusive program at her public 4-year college which began accepting students in 2010. (find). Jane first began working with individuals with disabilities at a summer camp when she was in high school and continued working with students throughout her career in a variety of educational settings. She has a B.A. in special education and took many additional courses at the master’s level and other trainings as needed. Jane was originally undecided in her major, but when it was time to pick a major and her advisor asked her what work experiences she’d had and he found out she already had years of work with individuals with disability, he suggested special education and she has enjoyed the career for over 25 years.

Jane mentioned proximity to disability in her family (mental illness) and said she was from a rural, low socio-economic background. She was the first in her family to attend college. She credited this background for her accepting attitude towards people with disabilities “from my experience, the more rural, the more poverty there is, the more



accepting that population is of differences.” She emphasized that individuals who go into special education should not pity people with disabilities because “this is a person with a disability, not just a disability.” Jane considered pity to be a form of discrimination because it limits opportunities for students with ID/DD rather than providing support and opportunities for real growth and development. Jane also mentioned that when she worked in a truly inclusive public school in which all opportunities were open to all students regardless of abilities, her advocacy for teaching and supporting students with ID/DD really began.

### **Javier**

Javier, a male in his 60s, was instrumental in founding, designing, and implementing the inclusive PSE at his 4-year public institution which began accepting students in 2014 after several false starts beginning as early as 2002. He has been a professor of special education at his institution since 1999 and currently holds the title of Associate Professor. He has a bachelor’s degree in social work, a master’s degree in business administration, and a Ph.D. in education and human resource studies with a concentration in special needs education. Javier teaches courses in the psychology of students with disabilities, psychological aspects of individuals with disabilities, applied foundations of contemporary special education, and multicultural aspects of people with disabilities.

Prior to his university position, Javier described significant work experience in group home management, independent living, and employment services for people with ID/DD and he also served on several disability advocacy boards. His education was spurred on by his work experiences with individuals with ID/DD and he continually

sought better solutions to their social, work, and housing needs. This desire led him into personal and professional relationships with Wolf Wolfensberger, the founder of Social Role Valorization, and with other lead thinkers in the field and he also had the opportunity to study at the Highlander Research and Education Center where the Civil Rights movement was formed.

Javier's main contributions to the conceptualization of inclusive PSE are advocacy and social justice. His advocacy skills are deeply rooted in experiences he had encountering the injustices faced by individuals with ID/DD and observing their vulnerability both personally and professionally. Javier actively pursued knowledge about social justice and the most contemporary information available on supporting individuals with ID/DD to live as the life they chose and to not be controlled by others. His social justice awareness comes from the knowledge he gained through educational experiences he sought out to answer the questions that his experiences provoked, particularly in the areas of social justice and the principles of normalization and social role valorization.

Javier was the only participant who wove subtle threads of equity through all of his planning including the insistence of precise language that forces a more inclusive stance. He "continually reminds the university community that they need to consistently move beyond allowing folks into our PSE Program to have these experiences to causing a climate and a culture that facilitates the students having those experiences." He emphasized "I do that all day, every day." Javier connects his role with broader social responsibility and takes a critical and confrontational stance against harmful, if unintentional practices that are "founded on centuries of unconscious bias assumptions about people who have been highly marginalized." Javier's advocacy emanates from

personal, practical and educational experiences deeply committed to principles of social justice and the principles of normalization (Wolfensberger, 1998).

## **Rachelle**

Rachelle is a woman in her early 30s with twelve years of experience working in inclusive higher education. She holds a bachelor's degree in biology, a master's degree in social work, and a Ph.D. in Special Education with a focus on program planning, administration, and evaluation. Rachelle had minimal experience with individuals with disabilities until she purposefully sought employment working with individuals with ID/DD so that she could get experience in a "helping field" while she considered applying to social work school. Her work in a privately owned group home was "probably my first experience, probably ever, with people with disabilities, that's what got me stuck in the field, not in a bad way...I got very attached to that population from the very first experience."

I still don't really know to this day what it is that I enjoy so much, I just really like being with the population, and I felt like I was contributing something that was important and also it just felt comfortable to do. I would rather spend time with them doing whatever it is that they were doing that day than talking to peers from class. I just really enjoyed it!

After graduating with her BA, Rachelle obtained a position as a resident assistant in the inclusive program where she has been employed for the last twelve years. In addition to her position as a resident assistant, Rachelle has been the director of resident life, director of their program's alumni center, and has experience working with students and parents, with curriculum and program design and fundraising. Her current role is

director of academics, innovation, and inclusion. This new role focuses on working with local school districts to form partnerships and create connections and scholarships for students with ID/DD who are from low socio-economic and minority backgrounds. Rachelle was also instrumental in developing their program's alumni association which provides lifelong support for individuals who went through the program and remain in the area to work and live. Because her institution is in a popular urban area with good public transportation, many of the students move there permanently, and the alumni program provides life-long support for graduates. She notes that parents are "blown away by the level of independence that their students acquire...making friends, riding public transportation...they don't really have a sense of what the outcome is going to be."

Rachelle sought her first experience working with individuals with ID/DD because she thought she wanted to work with individuals with disability, but she didn't have any practical experience. Her work in direct care with adults with ID/DD solidified her decision to pursue a master's degree in social work. Rachelle is in a unique position because her work began at a PSE that was established since 1982 and has over 700 alumni. She began her job before the HEOA was passed allowing her an up-close glimpse of the rapid changes that have taken place since 2008, and she was familiar with the people working at Think College before it was even established as a formal entity. Rachelle's work with the alumni center and her new role with community outreach are both profound contributions that raise the bar for program design. The alumni center provides lifelong support for students after they graduate, and the community outreach is a new initiative targeting students with ID/DD from low socio-economic and minority backgrounds.

Rachelle's motivation to work with this population is equally distributed between her personal disposition and desire to help others and she said she was glad she found such a good fit early in her career. Rachelle also has a firm belief that students with ID/DD can benefit greatly from these types of programs and when I asked her how she sought professional development, she said "learning from the students is the biggest thing." Rachelle said that in her master's social work courses were steeped in social justice and that social justice was a major focus at the institution where her PSE is located. "It's always been part of my work culture" she noted.

## Appendix C

### Consent and IRB Approval



In future correspondence please refer to 2018277

February 9, 2018

Tamara Shetron  
c/o Dr. Jodi Holschuh  
Curriculum & Instruction  
Texas State University  
San Marcos, TX 78666

Dear Tamara,

Your IRB application titled, *Students with Intellectual Disabilities in Postsecondary Education: Institutional Barriers and Facilitators*, was reviewed by the Texas State University IRB. It has been determined that risks to subjects are: (1) minimized and reasonable; and that (2) research procedures are consistent with a sound research design and do not expose the subjects to unnecessary risk. The IRB determined that: (1) benefits to subjects are considered along with the importance of the topic and that outcomes are reasonable; (2) selection of subjects is equitable; and (3) the purposes of the research and the research setting is amenable to subjects' welfare and producing desired outcomes; that indications of coercion or prejudice are absent, and that participation is clearly voluntary.

1. In addition, the IRB found that you need to orient participants as follows: (1) Signed informed consent is required; (2) Provision is made for collecting, using and storing data in a manner that protects the safety and privacy of the subjects and the confidentiality of the data; (3) Appropriate safeguards are included to protect the rights and welfare of the subjects.

**This project is therefore approved at the Expedited Review Level until January 31, 2019**

2. Please note that the institution is not responsible for any actions regarding this protocol before approval. If you expand the project at a later date or use other instruments, please re-apply. Copies of your request for human subjects review, your application, and this approval, are maintained in the Office of Research Integrity and Compliance. Please report any changes to this approved protocol to this office.

Sincerely,

Monica Gonzales  
IRB Regulatory Manager  
Research Integrity and Compliance  
Office of the Associate Vice President for Research and Federal Relations  
Texas State University

OFFICE OF THE ASSOCIATE VICE PRESIDENT FOR RESEARCH  
601 University Drive | JCK #489 | San Marcos, Texas 78666-4616  
Phone: 512.245.2314 | fax: 512.245.3847 | WWW.TXSTATE.EDU

*This letter is an electronic communication from Texas State University-San Marcos, a member of The Texas State University System.*

Renewed #5459 – Expires 1/31/20

## INFORMED CONSENT

Study Title: Students with Intellectual Disabilities in Postsecondary Education:  
Institutional Barriers and Facilitators

Principal Investigator: Tamara Shetron Faculty Advisor: Dr. Jodi Holschuh  
Email: [tamarashetron@txstate.edu](mailto:tamarashetron@txstate.edu) Email: [holschuh@txstate.edu](mailto:holschuh@txstate.edu)  
Phone: (512) 484-8603 Phone: (512) 245- 2157

Dear Participant,

This consent form will give you information needed to understand why this research study is being conducted and why you are being invited to participate. It will also describe what you will need to do to participate as well as any known risks, inconveniences or discomforts that you may have while participating. We encourage you to ask questions at any time. If you decide to participate, you will be asked to sign this form and it will be a record of your agreement to participate. You will be given a copy of this form to keep.

### PURPOSE AND BACKGROUND

You are invited to participate in a research study to learn more about inclusive campus practices for students with intellectual disabilities. The information gathered will be used to facilitate understanding and dialog between postsecondary education programs for students with intellectual disabilities and other non-program campus programs that support diversity and inclusion. You are being asked to participate because you are a director or administrator at a postsecondary education program for students with intellectual disabilities on a college campus.

### PROCEDURES

If you agree to be in the study, you will be asked to participate in three interviews on your campus when possible, at a time and place convenient for you, or via an online meeting platform or phone call if that is not possible. Interviews will begin held during the months of January and February 2019. Each interview will last approximately 60-90 minutes. During the interviews, you will be asked about your prior personal and professional experiences with individuals with intellectual disabilities, as well as your personal beliefs about individuals with intellectual disability. The interviews will also include your perceptions and observations of inclusive education for students with intellectual disabilities on your campus. The interview will be audio recorded and the researcher may take notes as well.

### RISKS/DISCOMFORTS

In the event that some of the survey or interview questions make you uncomfortable or upset, you are always free to decline to answer or to stop your participation at any time. Should you feel discomfort after participating and you are a Texas State University student, you may contact the University Health Services for counseling services at list (512) 245-2208. They are located 5-4.1, LBJ Student Center, 601 University Drive, San

Marcos, TX, 78666. Non-Texas State students may either (1) contact the counseling center at their home institution, or (2) Contact the academic advisor, Dr. Jodi Holschuh, or the researcher, Tamara Shetron, for further instructions on how to obtain assistance in this matter.

IRB approved application #2018277

11307  
02/09/  
2018





## BENEFITS/ALTERNATIVES

Anticipated benefits for the participants are that they will gain a better perspective of how their prior personal and professional experiences with individuals with intellectual disability and their beliefs about intellectual disability contribute to the success of their program. This knowledge may suggest best practices for professional development and training for other individuals working with students with intellectual disability and may lead towards the increased professionalization of the field of inclusive higher education

The benefits of the study extend beyond the three campuses and may suggest new ways of approaching campus personnel across campus systems for administrators and directors of other programs too.

The information gathered in this study may also serve as a first empowerment step in creating a campus self- advocacy protocol for students with ID to begin their own conversations with other services across the campus (diversity groups, etc.).

## EXTENT OF CONFIDENTIALITY

Reasonable efforts will be made to keep the personal information in your research record private and confidential. Any identifiable information obtained in connection with this study will remain confidential and will be disclosed only with your permission or as required by law. The members of the research team, and the Texas State University Office of Research Compliance (ORC) may access the data. The ORC monitors research studies to protect the rights and welfare of research participants.

Your name will not be used in any written reports or publications which result from this research. The research data will be kept for three years (per federal regulations) after the study is completed and then destroyed.

## PAYMENT/COMPENSATION

You will not be paid for your participation in this study.

## PARTICIPATION IS VOLUNTARY

You do not have to be in this study if you do not want to. You may also refuse to answer any questions you do not want to answer. If you volunteer to be in this study, you may withdraw from it at any time without consequences of any kind or loss of benefits to which you are otherwise entitled.

## QUESTIONS

If you have any questions or concerns about your participation in this study, you may contact the Principal Investigator, Tamara (Tami) Shetron. (512) 484-8603, [tamarashetron@txstate.edu](mailto:tamarashetron@txstate.edu)

This project was approved by the Texas State IRB on [date]. Pertinent questions or concerns about the research, research participants' rights, and/or research-related injuries to participants should be directed to the IRB Chair, Dr. Denise Gobert 512-245-8351 –

(dgobert@txstate.edu) or to Monica Gonzales, IRB Regulatory Manager 512-245-2334 - (meg201@txstate.edu).

#### DOCUMENTATION OF CONSENT

I have read this form and decided that I will participate in the project described above. Its general purposes, use the particulars of involvement and possible risks have been explained to my satisfaction. I understand I can withdraw at any time.

---

Printed Name of Study Participant

---

Signature of Study Participant                      Date

---

Signature of Person Obtaining Consent                      Date

I acknowledge that this interview will be audio recorded and authorize the use of audio equipment to record my voice.

---

Printed Name of Study Participant                      Signature of Study Participant  
Date



## **Appendix D**

### **Interview Protocol**

#### **Interview One: Personal Experiences**

##### **Domain 1:1**

##### **Demographic Questions:**

1. What is your full name? (a pseudonym will be used for transcription, coding, and all reporting)
2. How old are you?
3. Where did you grow up?
4. How long have you held your current position?
5. What previous positions have you held similar to this one?
6. What previous positions have you held that are not related to this position?
7. Any other prior work experience you'd like to share?
8. Describe for me your educational background, course of study?
9. Tell me about any training that you have had specifically relating to individuals with ID or disabilities in general
10. Tell me about any educational experiences we haven't discussed that have contributed to your success in your role as administrator of your program

##### **Domain 1:2**

##### **Early Disability Awareness**

Now we will discuss your early awareness of individuals with disabilities

1. Describe for me your earliest awareness of individuals with disabilities/intellectual disabilities
2. If you have one, and are willing to share, would you describe your own disability story?
3. Tell me about some experiences you have had through the years with individuals with intellectual disabilities
4. Tell me about your decision to seek employment with individuals with ID?
5. Describe for me a successful moment you had working with individuals with ID?
6. Describe for me a time that didn't go so well
7. What might you have done to change this situation?
8. What are the most important things you think people need to know when working with students with ID?
9. What are your favorite things working with students with ID?
10. What are the hardest things working with students with ID?

#### Domain 1:3

#### Jobs in the Field

1. 1.Tell me about jobs you've had in the same field?
2. 2.Tell me about your preparation for this job
3. 1.Specific training?
4. 2.On the job?
5. 3.Continuing education?

#### Interview Two: Professional Experiences

#### Domain 2:1

## Program Information

1. How old is your program?
2. Who started your program?
3. What was the person or group's motivation to start the program?
4. Can you tell me the story of the program's origination?
5. How is your program funded?
6. Where is your program organizationally seated at your institution?
7. What institutional supports do you get as administrator for this program?
  - Space?
  - Funding?
  - Personnel?
  - Emotional?
8. 5. Other resources (books, professional organizations? Training?)
9. Describe for me the services, programs, and activities your students participate in
  - Campus life
  - Dormitory
  - Dining
  - Clubs
  - Extracurricular
  - Support services (ODS, Diversity)
  - Any other?
10. How do you support your students in accessing these inclusive experiences? (i.e. provide peer supports, etc.)

## Domain 2:2

### Your Role in Student Experiences

1. How do students benefit from being in your program?
2. What are student outcomes?
3. Certificates? Degrees? Employment?
4. Describe a few of the most positive experiences you've observed your students have within your program
5. Describe your role in this experience
6. Describe a few of the most positive experiences you've observed your students having with campus programs or services outside of your program
7. Describe your role in this experience
8. Describe a few of the most negative experiences you've observed your students having within your program
9. Describe your role in this experience
10. Describe a few of the most negative experiences you've observed your students having with campus services outside of the program?
11. Describe your role in this experience

## Appendix E

### Sample Codes and Analysis

**Access**  
**Administrators**  
**Administrator/Ed**  
**Admin. Work**  
**Advocacy**  
**Affective**  
**Agency**  
**Allies**  
**Assist**  
**Authentic**  
**Relationship**  
**Awareness**  
**Axiological Beliefs**  
 Barriers  
**Blend in**  
 Bullying  
*Campus Culture*  
**Change over time**  
 Charity  
**Citizenship**  
**College**  
**College experience**  
*Consequences*  
 Critical Incident  
**Daily Experience**  
**Deepen Democracy**  
**Dialog**  
**Dignity of risk**  
*Disability*  
**Disability Support**  
**Diversity**  
*Easy*  
**Education/process**  
**Education/product**  
**Effective**  
**Emancipate**  
**Energize**  
**Equity**  
**Ethics**  
**Experience**  
*Families*

Fear  
**Feelings**  
**First reaction**  
**Formal education,**  
**non-formal education**  
*Hard*  
**Humanization**  
**Identifying**  
**Inclusion**  
**Independence**  
 Ineffective  
**Inequity**  
**Instruction**  
**Intellectual**  
*K-12*  
**Knowledge production**  
 Knowledge reproduction  
 Labels  
 Lack of Diversity  
**Language**  
*Laws*  
 Liability  
**Liberate**  
*Life is the ultimate*  
*Curriculum*  
 Limited Opportunities  
*Logical*  
 Lowered expectations  
**Network**  
**Opportunity**  
**Organiz/Power/oppress**  
**Organiz/Power/Lib**  
*Parents*  
**Participation**  
**Pathways to change**  
**Peer**  
**Person Centered**  
*Pervasive*  
 Pity  
*Professors*  
*Proximity*  
**Resources for Job**

**Rights**  
**Self-Advocacy**  
**Self-Determination**  
 Shame  
**Social**  
**education/learning**  
*Social*  
*Inclusion/Exclusion*  
*Societal Norms*  
*Special Education*  
**Staff**  
**Standards**  
 stigma  
 Stigmatizing  
**Student development**  
**Support**  
**Training**  
**Understanding**  
**University-opportunity**  
 Untrained Staff/Faculty  
*Values*

#### Key:

**Bold Underline:**  
 Critical/Freire

**Bold:** Supportive

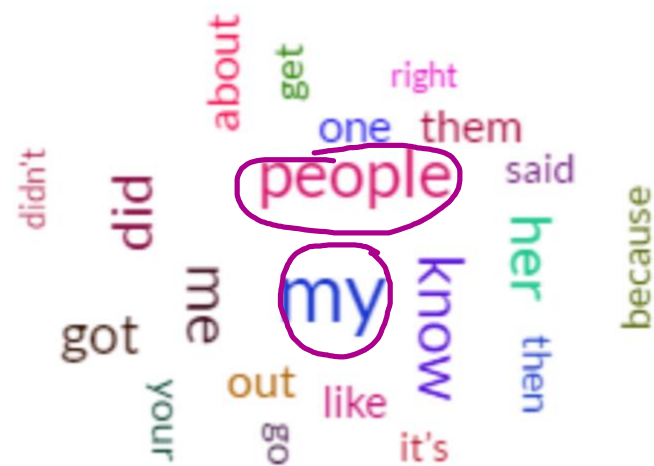
*Italicized:* Can be positive  
 or negative – needs  
 further exploration

Strike through: Negative  
 experience

### Example of Daphne's Word Cloud

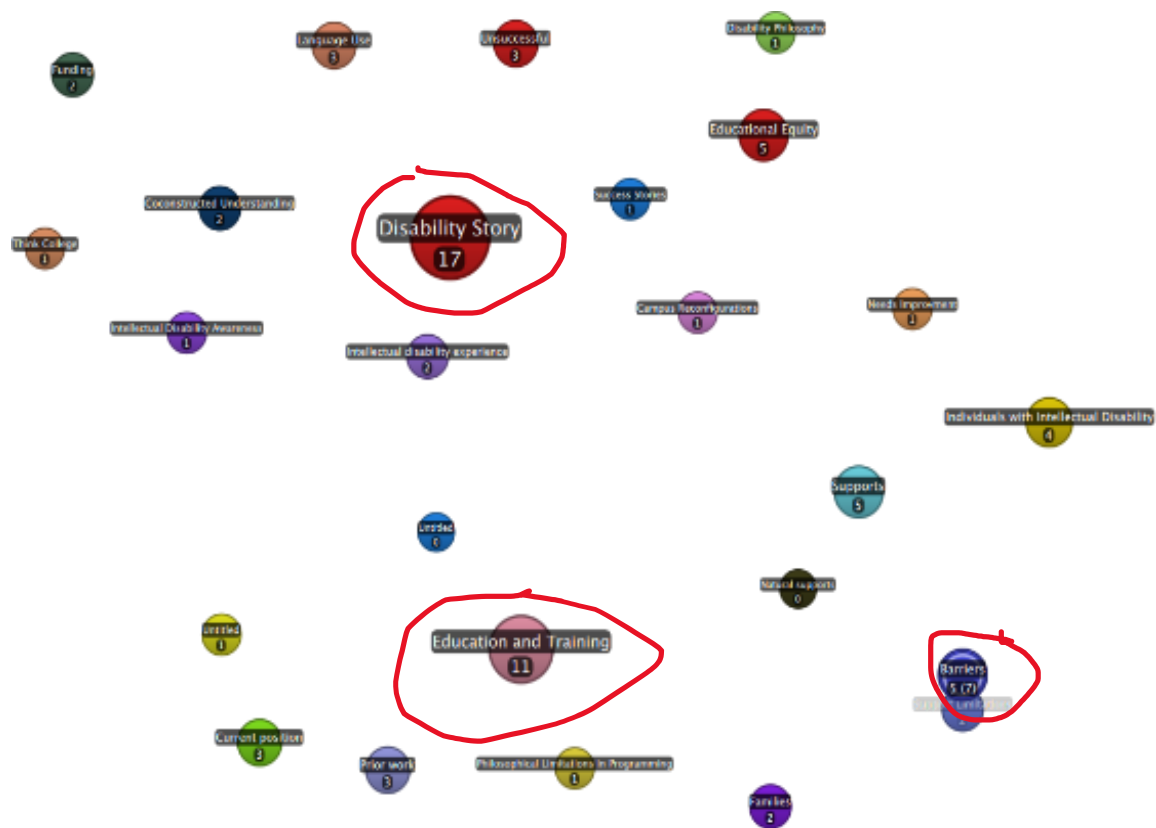


### Example of Javier's Word Cloud



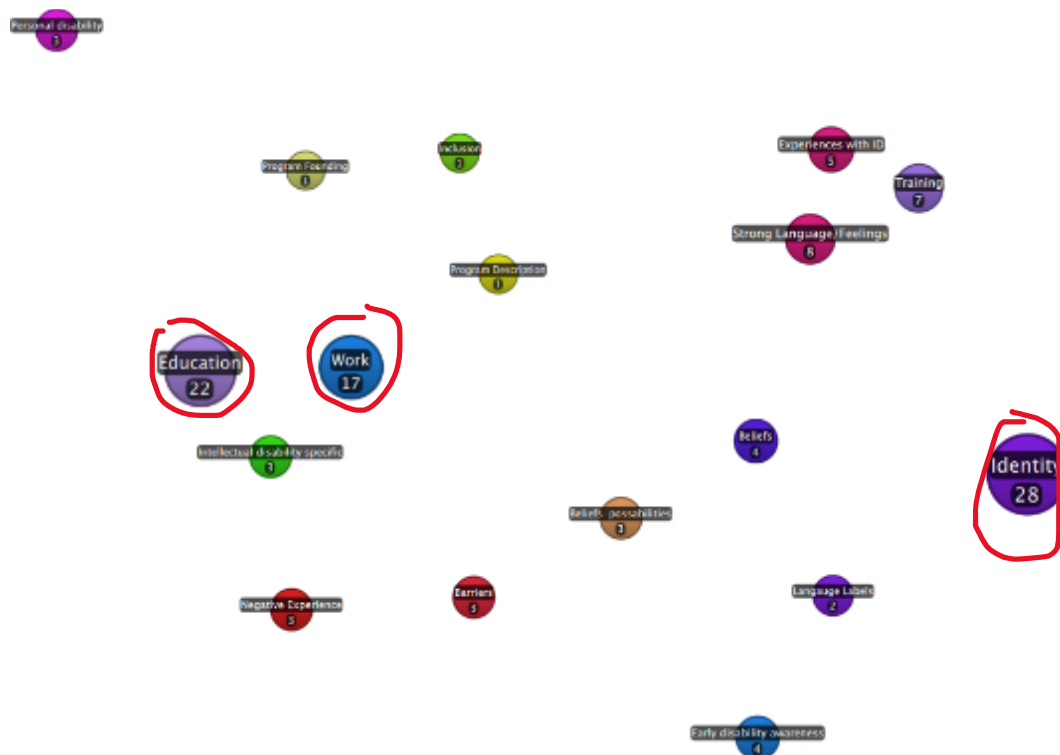


Data Chunking



Summary of Chunking Themes: Daphne Top Five Themes

Theme	# of Occurrences
Disability Story	17
Education/Training	11
Barriers	5
Support	5
Educational Equity	5



Summary of Chunking Themes: Ethel top five themes

Theme	# of Occurrences
Identity	28
Education	22
Work	17
Emotional Language/Feelings	8
Training	7

## Appendix F

### My Disability Story

#### Obscene

*The term obscene comes from classical Greek theatre and refers to any action considered too indecent to portray on stage, but which might be implied by moving the scene off stage to be continued in the audiences' imagination.*

My disability story is the story of pervasive proximity to disability and the loss and fear I experienced as a young girl watching my family fall apart and being left behind, alone to watch my mother lose her health and mobility as she battled a degenerative, debilitating, non-diagnosable, neuro-muscular disease. My mother's disease affected her balance, her peripheral vision, and her ability to feel and control her hands. For a time, it also affected her esophagus. This meant that she had difficulty swallowing and choked frequently.

My mother was a highly intelligent, classically trained musician who approached her disability like a researcher. Her disability experiences were heightened having taken place in the mid-1970s, at the epicenter for disability studies: Syracuse, NY. Her medical care was supervised by a research neurologist, Dr. John K. Wolf, and as the effect of disability on the quality of life of people was beginning to take precedence over medical definitions of disease, together they explored every aspect of how the disease progressed and how it affected her life and wellbeing. In his books on Living with MS written in 1984 and 1987, her photo is featured multiple times on the covers and inside next to her contributions.

Years later, coming to my own childhood experiences with an adult, critical self-reflective researcher lens, I now have the tools to objectively consider my experiences. At this point, I discover myself standing at the periphery of every photograph and story in these books. For I am there, a child, living this experience with her, in the back seat, sitting through endless MS meetings, opening doors for her wheel chair bound friends, going to physical therapy appointments, driving hundreds of miles for her to try alternative therapies, being dumped at strangers houses while she had surgery. By 10, I had developed an ulcer, and by 12, I had buried myself in a cloud of marijuana smoke.

#### Critical Incident

Outside of the support groups, the doctor visits the research, and the books, is the very real, day to day experience that are the reality of living with disability. At home, my role was not obscene, it was very much a role of frightened proximity. I share one event from this time which I had not remembered until I explored my relationship with my mother's disability using my adult critical self-reflective lenses. As an adult who has raised children, I now see what a horrific, lonely position I was put in as a young adult.

Our meals became a frightfully bizarre and frightful nightly event. Home cooked meals at the table watching Star Trek, M.A.S.H., or the nightly news on the small black and white TV in the kitchen were punctuated by her choking episodes. My role was to gauge the level of severity and respond "appropriately." Like a well-trained dancer, I had a series of choreographed moves developed in response to the length and severity of the episode. Response was to (1) stop everything and focus on my mother, (2) wait and see if the choking stopped or became prolonged, (3) prolonged choking involved

providing Kleenex at intermittent intervals to wipe her watering eyes, spittle and dislodged food chunks. The episodes varied in length and severity and were accompanied by various non-verbal communication ranging from calmly reaching for a Kleenex, to frantic foot stamping.

For me, these were nightly deer-in-the-headlight moments. Moments of required external action yet inwardly frozen. There were 1, 2, and 3 Kleenex episodes accompanied by gesturing and food-stomping. Beyond 3-kleenexes, my instructions were to “go in my bedroom and get the oxygen tank.” I was taught how to turn on the tank and put the mask on her. This was before 911, and for some reason, no one ever thought about instructing me what the NEXT step would be or providing me with any type of adult back up support in my situation.

Then it happened: One evening, her choking got out of hand. It proceeded through all three Kleenex levels to the scary oxygen level, and then beyond. My insides churned as I stood by helplessly while she stomped her foot and I handed her Kleenex after Kleenex to wipe her eyes and mouth. For the first time in my life, I realized that there was another step...lack of oxygen meant passing out, which meant that my mother was going to black out and fall to the floor in front of me, and I was completely helpless to stop this.

Nobody had trained me for the next step, nobody told me what to do or who to call. This was before the internet and 911. In my panicked helplessness and horror, I just knew that I couldn’t watch this happen, so I walked out the room, and watched through a

crack in the door. Frozen, frightened and appalled that I had abandoned her in this moment.<sup>1</sup>

Thankfully she recovered, but we never talked about it, and I couldn't wait to leave home and get away from, what I now recognize as a forced caretaker role. Even all these years later I wonder why nobody ever offered me a phone number to call, trained me to call the police, or even realized or cared that I was living with experiences like this on a day to day basis.

I had never told anyone about this incident until it came to my mind while talking to that young man who had questioned me about my disability story. These events were just a regular part of my childhood, but they weren't regular childhood events.

---

<sup>1</sup> I recently came across a literary description of what I describe in my story. In Margaret Atwood's short story; *The Art of Cooking and Serving*, (2006), she describes a young girl, eleven years old, who is living with her pregnant mother on a remote island. The father works somewhere else and comes home on the weekends. The girl describes her worry about what to do if her mother goes into labor when they are alone. After going through an exhaustive list of options, she concludes "I would just have to do it anyway. It was either that, or my mother would...Would what?" As she tries to imagine what would happen if her mother did not get assistance while giving birth, she continues "Here my mind would cut out..." My mind also "cut out" periodically while dealing with my mother's disability.

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