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The Words and Worlds of Disability: Discourses on Disablement Within the Situated Practices of Service Providers

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THE WORDS AND WORLDS OF DISABILITY:
DISCOURSES ON DISABLEMENT WITHIN THE SITUATED PRACTICES OF
SERVICE PROVIDERS

By

ENITZA C. CARRIL

A dissertation submitted to the Graduate Faculty in Psychology in partial fulfillment of the
requirements for the degree of Doctor of Philosophy, The City University of New York
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This manuscript has been read and accepted for the Graduate Faculty in Psychology in satisfaction of the dissertation requirement for the degree of Doctor of Philosophy.

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ABSTRACT

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by
Enitza C. Carril

Advisor: Dr. Anna Stetsenko

From a traditional perspective, disability stood outside the normal bounds of development, belonging within the realm of pathology and the disabled person was defined as deficient. Disability may also be characterized as an instance of human diversity and disabled as a designated identity that is socially constructed in an ongoing process—an interaction between individuals and social contexts. The process of disablement is linked to discourses used to define and act upon people ascribed with a disabled identity. This study assumes that disability is an instance of human diversity, a valid developmental trajectory, which is enacted and embedded in sociocultural, political, economic, historical, and discursive contexts. Discourses contribute to how disability is understood and then enacted in policies and situated everyday practices. With a focus on the human service delivery system for developmentally disabled people, I assessed discourses and conceptualizations of disability enacted by service providers through narrative inquiry. I also collaborated with service providers through a focus group discussion, guided by sociocultural theories on teaching and learning, to introduce neurodiversity and disablement as a contextualized process. The results of this study suggest the situated nature of discourse, with
varying language as it relates to local practices. Situated practice-based discourses enacted “on the ground” were in tension with local/service-driven and deficit-based languages. The ways of conceptualizing and understanding disability, however, were consistently that of a socially contextualized construct. Service providers negotiated different positions in attempts to exercise agency and contest the designation of passivity attributed to disabled people they work with. Their language, however, varied and incorporated deficit-based, local, and situated practice-based discourses. Although disability is understood as a complex process beyond personal deficiency, discourses appear to remain in transition.
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My parents, Emilio and Alicia, are my motivation. I would like to thank them for teaching me what it means to love and believe without conditions or bounds. Their unrelenting belief in me has given me the strength and confidence to succeed even when belief in myself wavered. I feel privileged to have them as parents and hope that one day I can be as good a parent as they have been to me.

My daughter, my inspiration—Karen, inspires me to persist no matter how difficult or daunting a task may seem. She has taught me how to laugh and enjoy the moment but most importantly she has given me purpose. I would like to thank Kelly Nagy for taking on so much while I have been figuratively away. Her support, encouragement, and motivational texts have been vital in making this a reality. I must also acknowledge Holly-Peno and Habi-Nero for their loyalty and companionship during the many long hours of dissertation writing. I have never felt alone with them by my side.
FOREWORD

The mockery made him feel an outsider; and feeling an outsider he behaved like one, which increased the prejudice against him and intensified the contempt and hostility aroused by his I defects. Which in turn increased his sense of being alien and alone. A chronic fear of being slighted made him avoid his equals, made him stand, where his inferiors were concerned, self-consciously on his dignity. (Huxley, 1932, p.69)

A *Brave New World* elicits images of a utopian world in which egalitarianism exists in a reified place; however, this utopia is a dystopia. In Huxley’s World State, eugenics, sterilization, classification, and subordination are part of daily existence. People are born—hatched—into their social categories and differences from imposed norms are not permissible in this totalitarian class system. Although an extreme world when compared to our society, the similarities are uncomfortably evident.

Comparable to the fictionalized World State, in our society identities and behaviors are prescribed according to normative predeterminations and are enforced through cultural narratives and discourses. These discourses define differences as intrinsic categories of inferiority that are situated within the person. Some categories are perceived as so immutable that they are accepted as inherently part of the self. Much like Huxley’s Bernard Marx, disabled people live in a world in which they are defined as outsiders and are subject to social oppression and exclusion. Social categories can be enforced through discourses, of mockery for Marx and discourses of deficit for disabled people.
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CHAPTER 1

INTRODUCTION

What does it mean to be disabled? Is disabled something that a person is or is it something that is done to a person? When disability is situated inside the person, often within the realm of the medical, the person is described as disconnected from sociocultural and historical processes and human practices. If disability is the defining factor in the positioning of a person, it can be used to socially construct – delimit, prescribe, regulate, and control core dimensions of a person’s life and development. Words and language that are loaded with judgments that enforce a particular social order are part of a process of disablement. How disability is understood also guides research, policy, and intervention that can foster a process of disablement or an opposing process, enablement (Pledger, 2003). When speaking of disability, dominant discourses reiterate and enact the position of the medical and deficit-based models that view disability as an illness and personal failure, while positing people as isolated from their sociocultural worlds and practices.

Contrary to deficit models, social conceptualizations of disability challenge dominant views and define disability as a historically emergent, socially constructed, and culturally situated category (Siebers, 2006). Deficit models focus on an individual’s lack of skills or abilities as they are relative to normative functioning. In social conceptualizations, processes such as social, attitudinal, and environmental barriers outside the person, are seen as determinants in social oppression and marginalization of people labeled disabled.
Disability also can be viewed as an interaction between a person and the context, influenced by mediating factors that contribute to the definition and experience of disability. For instance, neurodiversity situates disability in an intersection between biological and social conceptualizations. Neurodiversity is a view that considers biological determinants as naturally occurring human variation but differences become deficit within a biased context that privileges normative functioning (Jaarsma & Welin 2012).

How disability as a human experience is viewed may be reflected in language and discourses. Discourses may also be relevant to creating and maintaining the label disability which in turn may affect everyday interactions and practices. The purpose of this study is to understand and critically review discourses enacted by service providers, direct support professionals in particular, within the service delivery system for developmentally disabled people. Direct support professionals work directly with disabled people and represent a group that can promote enablement or disablement. By analyzing participants’ discourses an attempt is made to deconstruct the ways that they theorize disability. Guided by the premise that language is instrumental in the construction of knowledge and self, which in turn drives practice, the goal is to understand the discourses enacted by direct support professional that may stem from larger cultural narratives that are consequential in services, policies, and practices.

Within the human service system, the understanding of disability is based upon deficit-based, clinical perspectives that relate to medical models of disability (Saleebey, 2006). Medical models undermine the complexity of the developmental process, as well as, the intentionality of people to enact change in their lives and environment. Within the human service system, policies such as person-centered planning contain elements of contextualized understandings of
developmental disabilities (O’Brien, O’Brien, & Mount, 1997). However, the pragmatics of everyday practices and institutional demands interfere with a truly person-driven approach that would enable autonomy and self-directed choice making (Holburn & Vietze, 1998; Antaki, Finlay, & Walton, 2007).

This study aims to introduce service providers to perspectives on disability based upon social, interactional, and dynamic models. The assumption is that disability is constructed within a disabling process that creates ephemeral but consequential social categories. This research focuses on introducing service providers to neurodiversity and disablement as a process. The conversation on disablement requires a paradigm shift based upon a worldview that sees disability as a multi-faceted experience. I propose understanding developmental disability as a naturally occurring aspect of human variation that is embedded in political, social, and economic contexts. The aim is to connect language, perception, and power. Based upon sociocultural theories of teaching and learning, I attempted to collaborate and engage service providers in order to introduce them to disablement and neurodiversity as alternatives to exclusively medical or social approaches. Additionally, I view participants as active agents, with the assumption that people are able to purposefully enact change in their own thoughts, life, and their society through practices.

This study also explores psychological agency and the dialogic self, the processes by which a person is shaped by the social context and in turn, through their own agentic activity, shapes the social process that the individual is embedded in (Stetsenko & Arievitch, 1997). Through a discussion of various theories of human development, as they relate to disability discourses—such as: the medical and social models, cultural-historical, dynamic systems
theories, and disablement—I present developmental difference as an instance of human variation that is socially constructed as disability. This kind of variation becomes a disability through a multi-faceted disablement process that is enforced by discourses that maintain socially oppressive attitudes and practices. The aim of this study is to understand service providers’ current discourses and ways of theorizing disability, and to introduce them to disablement and neurodiversity.

Situating the Researcher

My interest in developmental disabilities began as a professional pursuit; however, it entered the realm of my personal life in an unexpected and transformative way. Following college graduation, I worked in a classroom with autistic children practicing applied behavioral analysis. From this experience my interest in autism, and developmental disabilities in general, grew. I did not pursue professional opportunities in this field due to my discomfort with the rigid teaching methodologies I learned while working with autistic children. Years later I would become the parent of an autistic child.

When I returned to the field of human service provision for developmentally disabled people, I worked with adults and children in day habilitation and residential settings. This work sparked my interest in self-advocacy activities. My academic and professional work both emphasized a social understanding of disability. Self-advocacy, in particular, grew as an area of interest as I saw its potential to serve as a catalyst for social and political change.

As part of my doctoral program research, I conducted a qualitative study and collected narratives from nine self-advocates who were part of Self-Advocates of New York States. The
Self-Advocates of New York State consisted of seventy-nine members statewide at that time. From these narratives I noted that impairment and disability were not mentioned as defining factors in self-representation by participants. This was evidenced by accounts from eight of the nine participants that did not make reference to their disability when asked to describe themselves. Other social categories were used to self-represent, such as: father, daughter, friend, woman, or religious affiliation. I also found that self-advocacy activities promoted psychological agency by creating a *figured world* (Holland, 2001). All participants expressed an identity transformation when they became part of this self-advocacy group. They described a change in their perception of self from someone who lacked capability to someone who was capable of doing things they did not think possible. They were transformed from people with disabilities into activists. By becoming part of this group and practicing self-advocacy activities, participants gained psychological agency, a feeling that they can have an impact on their world.

The project with the Self-Advocates of New York State served as the starting point and has informed my current dissertation research. This work led to my interest on the relevance of discourses to conceptualizations of disability.

In my personal life, the birth of my child marked a developmental shift in my own self-identification as a parent but this perception would soon take a new course. My daughter was diagnosed with autism shortly before her second birthday. *My self* as a professional in the field of human services and *my self* as a student of human development were now secondary to my new identification as parent of an autistic child. The emotional experiences and journey through early intervention and preschool education changed my worldview. From within the daily microcosm of what were labeled repetitive behaviors and language delays, I became starkly
aware of a pervasive deficit model manifest in professional jargon through interactions with teachers and therapists. The term deficit implies lacking favorable traits and as Mazher (2012) described, “the word deficit is synonymous with behavioral and social problems. Such students are metaphorically incomplete, as containers that miss a sufficient amount of a good thing” (p.782). Deficit and delay became the dreaded classifiers that were used to describe my child as a person that lacked elements of complete personhood.

Now as a parent, I heard labels and lists of deficits. I became keenly aware of a professional discourse that was used to scrutinize my daughter’s actions through a lens of pathology that was relational to normalized child development. Even mundane actions were labeled autistic and served the purpose of confirming the diagnosis. As a student of developmental psychology, I learned that development is a dynamic interplay between multiple variables. But assessments and discussions of my child’s development were reductionist, conclusive, and placed her in an immutable category that would set the stage for the rest of her life. She was now a them in the proverbial us and them binary. I stood with her on the outside as we were spoken of and about by professionals who knew us only momentarily but were somehow experts on our lives. Our actions were analyzed, discussed, classified, and reported. For the first time I felt the judgment of the Foucauldian clinical gaze. Psychological definitions were now assigned to our new imposed identities: the child with autism and the autism parent.

There was a constant reminder of normal development—where my child should be and where she actually was. The disparity between normal and her individual development cast a shadow on the moments of playfulness and fun that are a part of early childhood. The
expectation of the child I was told she should have been, began to impede the enjoyment of the child before me. I began to see deficit and delay. I began to feel afraid of autism and disability.

Through self-reflection and research, my perspective began to change. I embraced the role of active agent capable of effecting change in our lives. My focus and purpose became changing the way that I personally spoke of and conceptualized autism. As a parent I became aware of the emotions elicited by words and terms used by professionals, a way of speaking that I came to refer to as the *lexicon of deficiency*. I did not want my child spoken about as a classification or a functioning level. So I began speaking about and describing my child through my terms. My words and thoughts concurrently changed. I no longer saw her through the lens of deficiency. She once again became the child she always was, mine. I can now enjoy and appreciate her as an intact, capable, and developing person whose future trajectory is as uncertain and limitless as any other child’s.

**Identity-first Language**

Prior to my child’s birth, my work and research with self-advocates introduced me to terminology that is preferred by some disability and autism rights advocates, identity-first language. I prefer to use identity-first language such as *disabled person* and *autistic person*, in contrast to commonly used person-first language. Person-first and identity-first language relate to theoretical models that are used as frameworks in definitions and discourses on disability. Minority or diversity models prefer identity-first language since it “construes disability as a function of social and political experiences occurring within a world designed largely for non-disabled people” (Dunn, 2015, p. 259). Kapp, Gillespie-Lynch, Sherman, and Hutman (2012)
found that “while autistic people and people who were aware of neurodiversity tended to prefer identity-first language, parents of autistic people and those with other types of relationships to autistic people did not have a preference for either term…consistent with the neurodiversity movement’s view that autism is central to identity, autistic participants and people aware of neurodiversity were more likely to prefer the term *autistic person* to the term *person with autism* than their counterparts” (p. 7). Autistic person validates a person’s identity (Johnson, 2013). The discursive presentation of identity does not simply describe a person but it is relevant and consequential in the ascription of disability as an illness or as a legitimate identity.

I also prefer to use the terms *non-disabled* and *non-autistic* in reference to people who do not identify as disabled. The Autism Network International, the first self-advocacy organization for autistic people, uses the term *neurotypical* to refer to people who are not autistic or neurologically diverse (Brownlow, 2010). Some autism rights advocates use *neurotypical* in order to move away from the traditional lexicon that sets the standard of the neurotypical person as *normal*. However, the term *neurotypical* seems to perpetuate the binaries of us and them, and typical and atypical.

**Person-first Language**

Person-first language emerged from the social model of disability and it was a move away from earlier language that was based upon moral and medical approaches (Dunn, 2015). The moral model used words that implied pity, charity, and even sinfulness such as *cripple* or *imbecile* (Dunn, 2015). The medical model, during the 19th century, introduced professional language relevant to impairment, such as “*the retarded, deaf-mutes, spastics, or feeble-minded*”
After the emergence of the social model, psychologists such as Beatrice A. Wright proposed that person should be prioritized over disability or impairment so the word person should be stated first (Dunn, 2015). Person-first language continues to be the preference of academics as evidenced by its acceptance by the American Psychological Association.

Person-first language, however, invalidates a disabled identity and disability culture, as it defines disability as something a person has: person with a disability, a person with autism (Johnson, 2013). Further, by setting disability outside the person, it deems it as something that is undesirable (Duffy & Dorner, 2011; Dunn, 2015). Person-first language also implies that there is “a normal person trapped behind the autism” (Jaarsma & Welin, 2012, p. 21).

When speaking of disability, language continues to develop and change. Language appears to be in transition and flux. Different discursive approaches place value or judgment on particular words and the language used in this study reflects personal comfort with elusive terms.

**Research Context**

This study is situated within New York State’s system of service delivery for developmentally disabled people. As a governing agency, The Office for Mental Retardation and Developmental Disabilities was created in 1977 after deinstitutionalization to address the need for services for developmentally disabled people; its name was changed to The Office for People with Developmental Disabilities in 2010 (“Overview of agency,” 2014). In New York State, The Office for People with Developmental Disabilities regulates and mandates policies that are enacted by both state-run and voluntary, non-profit organizations. Some of the services these organizations provide include: day habilitation programs, residential services, supported
employment, and recreational programs. Participants, for this study, are employed by a non-profit organization that is regulated by The Office for People with Developmental Disabilities.

**Legal Definitions of Disability**

Under The Office for People with Developmental Disabilities, service eligibility is exclusively for people who fit the legal definition of developmental disability under the New York State Mental Hygiene Law (“Guide to Understanding Supports,” 2012). This specific definition of developmental disability is published by The Office for People with Developmental Disabilities as follows, “developmental disability means a disability of a person who is attributable to mental retardation, cerebral palsy, epilepsy, neurological impairment, familial dysautonomia, or autism or attributable to any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons or requires treatment and services similar to those required for such persons” (Guide to Understanding Supports, 2012). Whereas according to the Center for Disease Control developmental disabilities “are defined as mental or physical impairments affecting daily functioning in three or more areas, such as self-care, expressive language, and mobility. Developmental disabilities manifest before age twenty-two and include different conditions, such as autism, epilepsy, and cerebral palsy” (Ward et al., 2010, p.281). The definition adopted by The Office for People with Developmental Disabilities uses the word retardation and considers developmental disability any condition that results in functioning and requires treatment as for mental retardation. It describes developmental disability as a personal attribute that requires treatment in order to more closely approximate normalized functioning. The Center for Disease Control, however, provides a more
contextualized view in which impairments interfere with daily functioning. Further, The Office for People with Developmental Disabilities’ definition considers disability as “a substantial handicap to such person’s ability to function normally in society” (“Guide to Understanding Supports,” 2012). The term *substantial handicap* becomes the defining factor that transforms an impairment into a disability as it interferes with a “person’s ability to function normally in society” (“Guide to Understanding Supports,” 2012). The expectation is *normal functioning* and the impairment creates the substantial handicap. In contrast, the Center for Disease Control uses the term *adaptive behavior* as opposed to normal functioning and by omission recognizes the stigmatizing effects of the term *retardation*. Although the differences may appear subtle, terms and words used in policies that define behaviors and categorize people become part of a local narrative that is consequential to situated practices.

**Language in Policies and Practices**

The Office for People with Developmental Disabilities adopts policies and practices that attempt to shift the driving force of service provision from the provider to the disabled person. Approaches and policies attempt to move away from traditional, institutionalized care towards individualized, person-centered services. Although current policies in the developmental disabilities service delivery system include discourses on person-centered approaches, the actual practice in everyday interactions is rooted in deficit-based models. The human service system has historically constructed a view based on medicalization. Through medicalization people are positioned as passive recipients of medical treatment and charity who are acted upon (Foucault, 1977). The language of policies and the policy-practice disconnects are also considered when theorizing context-situated research “on the ground.”
When people are viewed as inherently deficient, from a medical perspective, the protection of health and safety become the reasoning for power and control. Current everyday practices, as described by Jenaro, Vega, Flores, and Cruz (2013), demonstrate “an over-emphasis on quality of care that focuses on control, power, health, safety, and categorization as opposed to quality of life that focus on social inclusion, self-determination, personal development, community inclusion and the provision of individualized supports” (p. 497). Health and safety become barriers when they serve the purpose of limitation of activities regardless of the person’s individual capability because disabled people continue to be viewed as in need of care. Further, services are created within the confines of programmatic or institutional limitations despite individual preferences and choices. As Jenaro et al. (2013) found “a change in the assumptions about what quality is and reflects a larger shift in the field, specifically from program-oriented, formulaic models of care to individually tailored supports based on individual choices and preferences” (p. 497). Written policies emphasize individual capability as is evidenced by person-centered planning, the service delivery principle adopted by The Office for People with Developmental Disabilities (“Person-centered planning,” 2014). As it will be further discussed, person-centered planning acknowledges the social barriers that perpetuate disability but in practice, individual potential growth is seen as inherently limited because of personal deficits. Mandates for individualized planning are in place but people who receive services are often made to fit around program capabilities.

The language of the service delivery system maintains a micro-culture, with a particular discourse that composes a local language or dialect, that positions disabled people in roles of weakness and passivity and delimits agentic activities. Jan Grue (2011) summarized the
experience of disabled people as “targets of intervention…the person with the impairment was
the one to be patronized, blessed, left to die of exposure, institutionalized, cured or rehabilitated”
(p.535). In situated practices, disabled people who receive services are not provided with
opportunities to engage in social activities, that promote overall human development and agency
when they are seen as deficient; therefore, service providers are positioned as decision makers in
the best interest of the person. Although self-determination and self-advocacy activities are part
of the human service dialogue, they are often associated with a paternalistic approach that
continues to position the professional as the expert. For instance, the work of Antaki, Finlay, and
Walton (2007) looked at choice-making opportunities for developmentally disabled people
within the context of a residential group home setting. Although service providers attempted to
facilitate independent choices, they had to conform to institutional limitations and goals that
ultimately removed the ability to make choices from the disabled person. Consequently, the
choices preferred by service providers were promoted and imposed by institutional demands and
the disabled person’s responses was geared towards that end (Antaki, et al., 2007).

Service Providers’ Self-Authorship

The way that service providers, direct support professionals in this study, self-identify and
represent their role and function is constructive of and constructed by greater social and
discursive traditions. As informed by Bakhtin’s heteroglossia and Holland’s dialogic self, the
way the self is spoken of and constructed is relevant to psychological agency (Asaba & Jackson,
2011). A sense of agency relates to service providers’ self-identification in their work within the
parameters of everyday service delivery and through interactions with service recipients.
**Heteroglossia and dialogic self.** Eric Asaba and Jeanne Jackson (2011) use Bakhtin’s notion of heteroglossia and Holland’s dialogic self to explain how social voices become part of the self. Asaba and Jackson (2011) described this process as, “self-authorship does not occur in the absence of social tensions and pressure, nor does it happen as a creative process situated solely within the person. Rather, we construct our sense of identities from preexisting social movements, practices, and discourses” (p. 143). The self does not exist in isolation and is created through the language and words of others. Holland, Lachicotte, Skinner, and Cain (2001) described, “in putting words to the world that addresses her, the “I” draws upon the languages, the dialects, the words of others to which she has been exposed” (p. 170). The “I” is inherently social through multiple languages, heteroglossia.

Bakhtin’s heteroglossia identifies inner voices as plural in nature, highly individualized but based in collective discourses (Bakhtin, 1984; Asaba & Jackson, 2011). The language of *ableness* becomes the standard through which meaning is made. As Mazher (2012) described, “language is governed by internal rules and techniques that enable it to proliferate in ways that constitute discourse. In this sense, the power of the ableness language, through which the non-labeled stand above the labeled in dichotomous relationship, becomes evident as the labeled adults position themselves in deference to science” (p. 787). The dominant narrative translates disability through deficit-based discourses grounded in medical views. This understanding is subsequent to a conceptualization of developmentally disabled people as sick, in need of care, and dependent upon others. The cultural narrative presents disability as a hard-wired, biological deficit situated inside the person.
Through internal dialogue the self is constructed referred to by Holland et al. (2001) as the dialogic self. The self is positioned in relation to others through dialogue, both external and internal. The discourses of the larger social context, as well as, the discourses of the human service industry are some of the voices that compose the dialogic self of service providers. The discourses they enact relate to their perception of self and the role that they play in their work.

Agency. The role service providers assume also relate to their perception of self as active agents in their ability to effect the lives of the people they work with. According to Holland et al. (2001) “identities are lived in and through activity and so must be conceptualized as they develop in social practice” (p. 5). Service providers’ ways of identifying are embedded in the social relations and practices of everyday service delivery through their activity and discourses. Service providers can act upon or act with disabled people as a result of and resulting in a power differential. When the disabled person is construed as passive they are treated as such, as Holland et al. (2001) wrote, “people learn to treat one another and themselves according to these categories” (p. 24). One group’s perspective becomes privileged over another due to social positioning. The self-representation of service providers as privileged over disabled people who are designated as service recipients is an artifact of situated practices. As Holland et al. (2001) described, “identities become important outcomes of participation in communities of practice in ways analogous to our notion that identities are formed in the process of participating in activities organized in figured worlds” (p. 57). The local context of everyday practice can be construed as a figured world.

A figured world is a domain in which people assert agency through engagement in cultural acts with others who share common characteristics (Holland et al., 2001). Figured
worlds utilize symbolic artifacts that are significant within their context. Additionally, participation in a figured world shapes a person’s behaviors and identity. Through meaningful engagement, people create an identity and construct meaning of their experiences. Holland et al. (2001) added to this by asserting that members leave behind their socially imposed identities and then form identities through participation in figured worlds. This results in the experience of agency which in turn shapes a person’s behaviors and transforms identity.

Agency as a psychological attribute is described by Haggard and Tsakiris (2009) as “a person’s ability to control their own actions, and through them, events in the external world” (p. 242). According to Ahearn (2001) “agency refers to the socioculturally mediated capacity to act’ (p. 112). She further asserted that agency is not limited to an individualistic expression but can occur by groups through the use of mediational tools, such as language. From this perspective, discourses and everyday practices become agentic actions enacted by service providers supposing that social, contextualized processes drive development. Within the service delivery system, agency can be displayed by service providers and the people they work with from within the figured world of local practices. When a person is perceived and described as a passive recipient, attempts to transfer control from the service provider to the person are undermined.

Research Proposal

This study attempted to understand the ways that disability is conceptualized by service providers and how their theories are enacted through discourses of disablement in situated practices. I also proposed the introduction of alternative perspectives to service providers that are based on the views of disability as a type of development that is neither pathological nor abnormal but rather the outcome of an interactive process of person and context that are
mutually constructive. I attempted to present developmental disability as a process, not a static category, by introducing service providers to ways of conceptualizing disability as a disablement process. People are seen as embedded in their culture. Development and disability are contextually situated in a greater cultural narrative that has the capability of enacting discourses of disablement or opposing discourses of enablement.

This approach is based on a belief that disability is a contextualized experience that occurs within a political, social, and economic framework embedded in historical traditions and practices. I attempted to engage participants so that they would consider disability as an aspect of human variation that is constructed through a disablement process rooted in social practices. The goal was to collaborate and engage participants dialogically through a focus group discussion and introduce disablement and neurodiversity as an illustration. This approach offers an understanding of developmental disability as neurological difference that is socially constructed as a deficit through a disablement process. By introducing these perspectives, I presented alternatives that differ from deficit-based or medicalized approaches and discourses.

To understand discourses in this context, this study also looks at current policies and systems within the human services delivery system. The current service paradigm uses a set of tools and practices referred to as person-centered planning. Guided by cultural-historical psychology and developmental contextualism, I attempt to gain insight into service providers’ discourses and ways of theorizing disability. I pose questions on the ways of conceptualizing and the ways of speaking of disability and attempt to introduce the interactional, dynamic, experiential, and deeply socially rooted nature of disability while recognizing neurological diversity as part of human variation.
In order to understand service providers’ ways of conceptualizing and speaking of disability and further collaborating in the introduction of disablement, I pose the following research questions: How do service providers conceptualize developmental disabilities? What language do service providers use to describe developmentally disabled people they work with? Is the language they use driven by cultural narratives, local/service-driven, or personal interpretations of developmental disability? Was meaning constructed through dialogic engagement?

**Background**

An understanding of the historical context and the lexicon of different time periods offers insight to the perceptions, attitudes, and treatment of disabled people. It also situates current views as they descend from a long history that fluctuates from intolerance to indifference to a search for acceptance. The following sections provide a brief overview of historical periods that are relevant to our current attitudes and discourses on disability. From this review, a connection is drawn between these historical moments and current practices and discourses.

**Historical Context**

During antiquity, the ancient Greeks and Romans had an idealized view of the body. Unlike post-modernity when normal has become the standard, ancient people strove for an idealized and flawless form. Classical ideals were based upon the idea of physical perfection (Elizabeth, 2008). Difference from the idealized form was thought of as disfigurement and an indication of inferiority. Even gender differences signified deficiency as Aristotle described women as a deformed, unfinished version of men (Gaardner, 1996).
During antiquity, the elimination of disabled children was practiced. Upon birth, infants were inspected and indication of physical difference allowed for the abandonment of the child (Edwards, 1996). This was a practice particularly prevalent in Sparta, which was a military-based community that relied heavily upon physical ability. Infanticide was a socially and legally accepted practice in both Ancient Greece and Rome. Ancient Roman law sanctioned the abandonment or killing of infants that were deemed undesirable. Under *Patria Potestas*, the father inspected the infant upon birth and had the option to abandon or kill the child (Nesbit & Philpott, 2008). Infants with a visibly identifiable difference were more likely to be experience paternal rejection and subsequent death.

The idea that difference at birth was impermeable to change was challenged by Hippocrates (Bollinger, 2003). He theorized an approximation to a medical approach by noting that corporeal and psychological differences come about through a mind-body relation. Hippocrates saw disease as the result of imbalances in humors and introduced the possibility of treatment and intervention. His views persisted into the middle ages.

During the Middle Ages, the perception of disability was based upon religious views. There were contradictory views that ranged from disability as a result of demonic possession to *village idiots* to the seemingly benign view of disabled people as *Les Enfants du Bon Dieu*—*Children of a Caring God* (Nesbit & Philpott, 2008). The religious view on disability during the Middle Ages, led to the establishment of orphanages and asylums that were run by religious organizations. These facilities provided custodial care but were not intended to provide education; the ideas of equality and potential ability were not the guiding principles in the treatment of disabled people.
Disabled children were thought of as perpetually innocent and even once they reached adulthood they were still seen as children. The infantilizing of developmentally disabled people has persisted into post-modern thought and practice. An example in our modern culture of disability as an infantilized human experience resonates in the controversial idea of the Pillow Angel (Baker, 2012). The term Pillow Angel arose from a series of medical interventions, known as the Ashley Treatment, used to hinder physiological development. Through surgeries, hormonal treatments, and other biomedical procedures a child's development is altered to maintain their present appearance and size. The purpose of the Ashley Treatment is to provide convenience for the child’s caregivers and spare the child the discomforts of adulthood, such as menstrual cramps for women. The image conveyed by the Pillow Angel is a helpless, sweet, eternal child lacking all of the complexities imbued on other human beings.

The Renaissance marked another shift in the definition and perception of disabled people. This was a time of cultural change when intellectual ideology and scientific inquiry emerged as ways of understanding the world. Along with science, health care and legislation showed marked changes that affected the lives of disabled people. For instance, in England, Queen Elizabeth I passed the Elizabethan Poor Laws of 1601 that made the government responsible for the care of the poor, including disabled people (Woodside & McClam, 2011). Under the Poor Laws, almshouses were created and maintained through taxation.

During the 17th and 18th centuries, philosophers' new ideas changed how disability was viewed. John Locke introduced the blank slate, tabula rasa, which provided the impetus for the idea that developmentally disabled children can be educated, learn, and develop (Goward, Grant, Ramcharan, & Richardson, 2005). Jean Jacques Rousseau believed that every person has worth
and can be a part of and contribute to society. He also believed that everyone can be responsive to education.

The idea that everyone can respond to education was exemplified by the case of *The Wild Boy of Aveyron*, Victor, and the work of Dr. Jean-Marc Gaspard Itard. Victor lived in isolation from human contact until the age of twelve (Lieberman, 1982). Dr. Itard implemented various educational and behavioral interventions to teach Victor language and other skills. Measured by normalized standards, Victor was not successful in reaching age correspondent abilities. However, Dr. Itard's approach demonstrated that individualized education is effective as he described, “when you begin with the nature of the child and his interests” (Lieberman, 1982, p. 566). Itard's work with Victor focused heavily on sensory experiences as the starting point for skill instruction. From his standpoint, every person is capable of learning when the method of instruction is based on the person's abilities. Despite spending twelve years in isolation, Victor was still capable of learning and developing.

Industrialization was a time of economic growth, particularly in cities, and it was also a time for social reform. Reformers, such as Dorothea Dix, spoke out against the poor conditions disabled people lived in (Grob, 1994). Dix contested conditions in alms and poor houses and advocated for land to be set aside by the United States government for disabled people. Similarly, Alexander Johnson (1899) proposed the creation of small communities of *mentally retarded* people in which some people would have been taught agricultural trades, in training schools, and these communities would have been self-sufficient. This proposal was referred to as the colony plan. The wages for their labor would be used to financially provide for the more severely *feeble-minded* who were unable to learn such trades. The goal of training was to relieve
the financial burden from society. In Johnson’s descriptions, institutional care should be permanent. The training schools that Johnson proposed were to resemble schools more so than traditional institutions. However, interns, as they were called at the time, only received training in order to function within the limits of the school. Johnson further described, “it has not been found practicable to discharge large numbers of the educated imbeciles to care for themselves and direct their own course of life” (Johnson, 1899, p. 469). Once people were placed in training schools, they were set outside of mainstream society both physically and ideologically.

Although social reformers’ intentions were progressive, these schools would give rise to modern institutions (Grob, 1994). Dr. Samuel Gridley Howe, who was a reformer with Dorothea Dix, established the Massachusetts School for Idiotic and Feeble-Minded Youth. Although Dr. Howe intended to teach people in order to reintegrate them into society, training schools provided limited teaching of skills and became places of custodial care. Students were no longer referred to as pupils but were labeled inmates and community reintegration was not an actual outcome once a person was institutionalized. Instead they were trained to live and work inside the institutions for an indefinite period of time. Institutions took the form of hospitals, with doctors as directors and administrators.

During the time of institutionalization, disabilities were clinically classified and labeled by terms considered derogatory by current standards. Jean-Etienne Dominique Esquirol, for instance, defined intellectual disability as consisting of two distinct categories: idiocy and imbecility (White, 1926). This lexicon became the standard in professional descriptions and were used as clinical classifiers of developmentally disabled people. Idiots were defined as capable of learning and Esquirol intended to prepare them to live in society. The word idiot is rooted in
antiquity and was used to refer to unskilled laborers. Similarly, during the 1300’s when the word entered the English language, it was used to refer to poorly educated people (Smith, 2009). *Idiot* became a diagnostic descriptor during the 1800’s and was used to categorize people with developmental disabilities. Esquirol’s other diagnostic category was *imbecile* and this classification defined people as incapable of learning (White, 1926). In addition to those diagnostic categories, in practice within institutions, medical directors segregated people according to their type of disability with separate wards for *epileptics* and *low-grades* (“Cottage plan institutions,” 2015). These terms are reminiscent of current categorizations of developmental disabilities with terms such as *low-functioning* and *high-functioning* that are still used in clinical settings to describe developmentally disabled people relative to normative standards.

During the nineteenth century in the United States, institutions became the conventional method for care. Institutions relied on medical views through which disabilities were treated as personal deficiencies and interventions were limited to the confines of the institution (Grob, 1994). Such practices were seen in New York State in two early institutions: The State Custodial Asylum for Unteachable Idiots established in 1827 and The Craig Colony of Epileptics established in 1894 (“Craig developmental center,” 2015). These institutions remained operational until the 1980’s.

Institutions and segregated communities served the function of preventing procreation but eugenics also emerged as a method that would minimize the perceived transmission of disability across generations. During the turn of the twentieth century, eugenics in the United States was founded on German philosophies at the time (Nesbitt & Philpott, 2005). Eugenics resulted in
social engineering programs with the goal of segregating disabled people from the rest of society. Based upon social Darwinism, principles of natural selection and survival of the fittest were applied to the social world (Hodgson, 2004). Francis Galton first coined the term eugenics and he promoted reproduction among non-disabled people, an approach referred to as positive eugenics (Burrell and Trip, 2011). During the nineteenth century, some theorists accepted eugenics as a guiding philosophy for social policy. Galton, for instance, saw the fertility of people that were deemed *unfit* or *unproductive* as detrimental to society. Discouragement of procreation turned into outright elimination of childbearing capabilities of people who were thought of as *undesirable*, through sterilization practices, Elimination of reproductive capabilities is the second facet of eugenics referred to as negative eugenics.

Negative eugenics attempted to achieve the fittest traits by eliminating the possibility of child bearing by those classified as *unfit*—or to use the term of the time *degenerate*. Negative eugenics was practiced through sterilization and even elimination of *undesired* people (“Francis Galton,” 2009). Degeneracy theory shaped sterilization laws in the United States. This ideological perspective was used to justify forced sterilization and institutionalization. Sterilization and institutionalization served to assuage public fear of disabled people since they were thought of as potentially dangerous, a drain to social and economic resources, and as a potential threat to the gene pool (Nesbitt & Philpott, 2005). The belief in the inter-generational propagation of unfavorable traits is exemplified in the response of Justice Oliver Wendell Holmes Jr. in 1927, in the case of Buck v. Bell. The decision in this case enabled the forced sterilization of Carrie Buck and set the precedent for thousands of sterilizations in the United States. Justice Holmes stated “it is better for all the world, if instead of waiting to execute
degenerate offspring for crime or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. Three generations of imbeciles are enough” (“Francis Galton,” 2009). More extreme measures emerged in German eugenics programs including the Aktion T4 that resulted in the murder of thousands of people in state institutions.

**The Medical Model**

The medicalized approach applied in institutional settings used to justify eugenics was based upon personal deficiency perspectives that located disability within the person. The authority of medical professional was privileged at the expense of disabled people. The medical model on disability provides a cultural discourse that identifies disability as an individual deficiency and a theoretical framework that situates disability inside the person. This model defines disability as a medical problem that must be acted upon in ways that address it as such. The medical model defines disability as a set of biological impairments that lead to deficiencies and the focus is on the lack of capabilities (Davis, 2006b). Disabled people are perceived as sick and in need of medical treatment in order to fix their bodies or minds. From this perspective disability is the result of genetic, biological, and psychological causes. Grue (2011) described it as “an ideological framework that reduces every aspect of the disability to bodily impairment, prescribes only medical treatment and normalization as appropriate interventions, and denies agency to disabled people while reserving power for medical professionals” (p. 540). The opinion of the medical professional was privileged as the disabled person was defined as deficient, incapable, and passive.

The medical model was validated as an approach to disabilities during the 20th century with advances in medical and rehabilitation sciences. The world wars during this time resulted in
a vast number of physical disabilities. Disability was defined by a quantification of physical limitations (Williams, 2001). Injured soldiers were assisted with rehabilitation and medical interventions. The emergence of polio at this time also resulted in physical impairments and the medical approach focused primarily on physical disabilities (Braddock and Parish, 2001). Physically disabled people would later lead in re-conceptualizing disability as a social construct.

**The Social Model**

The 1960’s was a time of social change that included the disability rights movement and a re-conceptualization of disability. The social model of disability originated through the political activism in the United Kingdom, as a reaction to the medical model’s deficit and pathology based assertions (Masala & Patretto, 2008). The British social model was initially conceptualized by the Union of the Physically Impaired Against Segregation and made a distinction between impairment and disability (Grue, 2011). In the United States, the disability rights movement ascribed disability as a minority status (Shakespeare, 2006). The United States’ movement began at the University of California Berkeley (Shapiro, 1994). Students who used wheelchairs began the Independent Living Movement and they demanded de-medicalization of disability, de-institutionalization, and the elimination of attitudinal, institutional, and structural barriers through the implementation of Universal Design.

In order to alleviate the consequences of social and cultural exclusion, the social model called for political action to remove social barriers and to provide disabled people with a positive collective identity (Shakespeare, 2006). According to Shakespeare (2006), “civil rights, rather than charity or pity, are the way to solve the disability problem” (p.199). From this perspective, it is not the individual that needs to change through treatment, interventions, or medication. Rather,
the social context needs to change by removing barriers and changing attitudes. The goal is to change contextual factors by eliminating barriers and empowering disabled people by providing them with the necessary tools to mediate their environment.

During that time, President John F. Kennedy launched the Combat Mental Retardation Panel (“National Plan to Combat Mental Retardation,” 2012). Over fifty years later the word *combat* would re-emerge in the discourse on developmental disabilities with the passing of the Combat Autism Act in 2006 (Olmstead, 2006). The Combat Mental Retardation plan was subsequent to actions by a growing parents’ movement that was actively seeking civil rights recognition for their children (“National Plan to Combat Mental Retardation,” 2012). Parents also found themselves defying professional opinions that deemed their children unable to learn and unworthy of equal educational opportunities. The Combat Mental Retardation pamphlet, developed by President Kennedy's panel, defined mental retardation as a symptom, not a disease. The goal of the panel was to prevent mental retardation but if prevention was not possible then provisions were necessary to ensure “the same opportunity for social development that is the birthright of every American child” (“National Plan to Combat Mental Retardation,” 2012). The panel intended to launch a “coordinated attack on the problem of mental retardation” but it was also acknowledged that the environment can reduce *incapacity* so that disabled people can serve as a resource for the benefit of the entire community. From this overview it appears that mental retardation was seen as an individual trait that was biologically based but its effects were mitigated or augmented by environmental factors. The Combat Mental Retardation panel was indicative of greater public awareness and interest in developmental disabilities.
De-institutionalization

Despite the emergence of the social approaches, the civil rights movement, and the Combat Mental Retardation panel, many developmentally disabled people continued to live in institutions until there was public disclosure of the poor conditions in those settings. Legal reform through the Civil Rights of Institutionalized Persons Act of 1980 was the result of public awareness of conditions in state institutions and it gave federal protection to people in institutionalized settings (“Civil rights of institutionalized persons,” 2015). The appalling conditions in American institutions for disabled people lead to public outcry and eventually a process of de-institutionalization.

An instance of conditions in institutions is exemplified by the pictorial depiction titled Christmas in Purgatory (Blatt & Kaplan, 1974). Christmas in Purgatory demonstrated the conditions in The Seaside institution in Connecticut. This project was the result of collaboration between researchers and legislators, namely Senator Robert Kennedy and Governor Nelson Rockefeller, who visited various institutions in the eastern United States. The authors, Blatt and Kaplan (1974) observed, “it does not require a scientific background or a great deal of observation to determine that one has entered the ‘land of the living dead.’ It does not require too imaginative a mind or too sensitive a proboscis to realize that one has stumbled into a dung hill, regardless of how it is camouflaged. It is quite irrelevant how well the rest of an institution’s -sic- program is being fulfilled if one is concerned about that part of it which is terrifying. No amount of rationalization can mitigate that which, to many of us, is cruel and inhuman treatment” (p. 5). Public awareness, legislative changes, and new treatment approaches would
emerge following de-institutionalization. The demise of institutions was followed by new approaches, such as community-based services and treatment paradigms based on normalization.

Normalization

After deinstitutionalization, normalization became the term that defined the service approach for developmentally disabled people. Normalization claimed that it eradicated institutions (Culham & Nind, 2003). In place of institutions, small community-based group homes became the modality for residential services as it approximated a normal living environment. Normalization, however, is based on the premise that disabled people should change their behavior and gain skills in compliance with a normative lifestyle and consequently earn a socially valued role.

Theories of normalization were adopted in the United States during the 1970’s (Culham & Nind, 2003). As coined by Bank-Mikkelsen, Head of the Danish Mental Retardation Service, normalization is “an existence for the mentally retarded as close to normal living conditions as possible” (Calhum, 2003, p.67). Bengt Nirje, director of the Swedish Association for Retarded Children, made reference to the lifestyle of the average person. Normalization asserted that “people who do not integrate, and therefore remain ‘different’, may find it difficult to become valued by others…Society may surmise those who are regarded as ‘different’, with what Wolfensberger terms ‘negatively valued differentness’ or social devaluation” (Calhum, 2003, p.68). Wolfensberger (1972) described disabled people as deviant and promoted assistance in the demonstration of normative behaviors, within their culture, in order to obtain a valued social role. A valued social role, however, implies the existence of a devalued social role.
Wolfensberger later changed the term normalization to social role valorization but maintained the idea of deviant groups receiving validation through socially imposed values (Wolfensberger, 1983).

Although normalization includes discussion on individual rights, it does not accept disability as a valid identity and the disabled identity only exists as relative to a reified norm. Normalization does not recognize disability culture and it does not define disability as a socially constructed category. Disabled as an identity, without relational comparison to non-disabled, is devalued and as Calhum (2003) wrote, “although not intended, normalization has also left a legacy of attitudes towards normality, with normal thought of from a moral standpoint and equated with good rather than bad…Normality has become antithetical to diversity and seen as something that can and should be prescribed” (p.71). A non-disabled identity and lifestyle is the imposed normative standard.

The qualification of normalcy is consequential in daily practice in the service delivery system as normalization becomes a justification for the professional imposition of particular actions and behaviors that are prescribed as normal and maintain the social categories of ‘us’ and ‘them’ between the service provider and service recipient. Calhum (2003) further described, “in Wolfensberger’s Social Role Valorization [also referred to as normalization] model, practitioners are charged with helping people with an intellectual disability do ordinary things, in order for them to gain social value, which has to be earned through being like us” (p.73). The enforcement of behaviors prescribed by service providers and professionals are what define the normal standard. An inability to function normally, was seen as a failure intrinsic of the person (Flynn & Lemay, 1999).
Neurodiversity

Disability as an intrinsic deficit is a characteristic of medical-based models that is contested by social models. Proponents of social models emphasize contextual factors, whether economic, social, or political that construct and maintain disability. Unlike medical approaches, social models situate disability outside of the person. An integration of these two approaches emerged through the civil rights movement that adopts neurodiversity as its guiding principle. The term neurodiversity is attributed to Judy Singer, a sociologist who self-identifies with Asperger’s, who claimed that the neurologically different represents a new addition to the familiar political categories of sexuality/gender/race” (Jaarsma & Welin, 2012, p. 23). For instance, homosexuality was once considered a pathology and diagnostically categorized in the Diagnostic Statistical Manual III but it was later removed as a psychiatric diagnosis and is now generally thought of as an aspect of human variation. From this perspective, autism is biologically-based difference, not disorder, that is an aspect of human variation as is gender, sexual orientation, and handedness (Robertson, 2010). Neurodiversity emphasizes difference instead of disorder.

Neurodiversity is a theoretical perspective that differs from medical models by defining neurological differences, such as autism, attention deficit disorder, and dyslexia as part of human diversity, not disorders or illnesses (Rothstein, 2012). People have both strengths and weaknesses and many difficulties are a result of social contexts that is designed for non-autistic people (Robertson, 2010). Neurodiversity has been adopted by some autistic self-advocates who embrace their unique skills from processing the world as an autistic person. Medical and deficit models have promoted research that focuses primarily on curing and eliminating neurological...
Neurodiversity, however, as Sarrett (2011) explained, “promotes the incorporation of autistic traits into a healthy conception of one’s identity. Here, the traits associated with autism add to, instead of take away from, the wholeness of the self…the idea that autism completes, rather than fragments, a person is in stark contrast to the messages relayed to the public through mass media representations” (p.148). From this perspective, autism is a trait that does not need to be cured or normalized. Research and theorizing can be devoted to improving the quality of life, and effecting changes in the everyday lives of autistic children and adults (Robertson, 2010).

Neurodiversity encompasses two aspects, firstly the reinterpretation of autism as an expression of the human genome that permits variability in neurological processing and functioning (Robertson, 2010). Neurodiversity accepts a biological construct in the claim that autism, for instance, is a naturally occurring aspect of human variation. Secondly, there is a social and political aspect to the neurodiversity movement that advocates for civil rights of neurologically diverse people. The Autism Rights Movement promotes neurodiversity and also defines autism as a type of neurological expression, not pathology (Robertson, 2010). Autism is “a difference to be respected, not a deficiency to be repaired or counteracted” (Owren & Stenhammer, 2013, p. 32). Challenges experienced by autistic people are subsequent to confrontation with an environment, both social and physical, that privileges non-autistic people. As Robertson (2010) asserted, “another important facet of the neurodiversity perspective is its recognition that difficulties experienced by autistic people are always contextual. The neurodiversity perspective contends that living in a society designed for non-autistic people contributes to, and exacerbates, many of the daily living challenges that autistic people
experience” (p. 2). Autistic people become disabled by a context designed for non-autistic people and by approaches that enforce normalization over adaptive skill acquisition.

Unlike neurodiversity, normalization emphasized the value of non-disabled or non-autistic social roles. Enactment of normalized roles and actions influence current approaches, such as person-centered planning which originated from theories of normalization (Holburn, 2002). Person-Centered-Planning has become the treatment approach of the current service delivery system for developmentally disabled people in New York state.

**Current Service Delivery System**

The current human services delivery system, as it relates to developmentally disabilities in New York State, adopts the principles of person-centered planning (“Person-centered planning,” 2014). Plan development relies on practices that attempt to move away from institutional, system-driven services. As described by The Office for People with Developmental Disabilities, services are individualized and intended to provide supports that are directed by the disabled person receiving services. To evaluate the success of person-centered plans, The Office for People with Developmental Disabilities poses the following questions: “Did the supports result in activities that are meaningful to the person? Did the supports help the person develop or maintain relationships that are important to them? Is the person experiencing a sense of safety and stability?” (“Person-centered planning,” 2014). In order to achieve desired outcomes, person-centered planning is the mandated process adopted by The Office for People with Developmental Disabilities.
Person-Centered Planning

As a service modality, person-centered planning came to prominence during the 1980’s. O’Brien, O’Brien, and Mount (1997) are considered pioneers and they described that “person-centered planning did not ignore disability, it simply shifted the emphasis to a search for capacity in the person, among the person’s friends and family, in the person’s community, and among service workers” (p. 481). The clinical voice of the professional does not play as prominent a role in service development as it did in traditional and behavioral approaches. Rather person-centered planning emphasizes getting to know the person and include the voices of family, friends, service providers, and the person.

In development of person-centered plans, O'Brien and O'Brien (1989) specified areas that can affect a person's quality of life and these areas are referred to as the five valued experiences. These experiences are: community presence, community participation, promoting choices, supporting contributions, and valued roles. Community presence includes inclusion and integration into ordinary spaces whereas community participation involves creating relationships with a network of people. Promoting choices enables a person to exert control and effect change in their life. Supporting contributions involves assisting people in demonstrating competence in something they are interested in with the purpose of attaining a socially valued role. Person-centered planning assumes the five essential experiences are the standard that is both desirable and relevant to everyone. These experiences relate to socially contextualized understandings of essential parts of human practices. However, they can be interpreted as enforcing goals that are the expectation of families, service providers, or imposed social roles.
Person-centered planning is based on a person’s “desires, strengths, needs, and dislikes” as the driving forces for service development (Renzaglia, Karvonen, Drasgow & Stoxen, 2003, p. 143). As described by Mansell and Beadle-Brown (2004), this approach requires environmental modifications and individualized services to fit the capabilities of the person. Person-centered planning steps away from older service approaches which emphasized the authority of professional service providers and attempted to fit people into program-based services. This change in approach also required a shift in bureaucratic attitudes that can make person-centered planning difficult to adopt (Holburn and Vietze, 1998).

Unlike older professional or clinically driven approaches to service development, person-centered planning involves the coordination of a circle of support that relies on the opinions of family members and support workers in the determination of services for people who may not be able to communicate their own wishes (Renzaglia et al., 2003). Person-centered approaches view the person’s challenges as attributed to a failure of the social network to create opportunities for the person (Flynn & Lemay, 1999). The social network plays an important role due to the emphasis on community inclusion and integration into society. The importance of the person’s family is acknowledged in that family members are the ones who know the person best and can collaborate with professionals to provide individualized services.

In addition to family involvement, engagement with the immediate community is promoted (Renzaglia et al., 2003). Referred to as community inclusion, this aspect of person-centered planning encourages friendships, neighborhood connections and the establishment of valued social roles. Community inclusion is a stark difference from the approaches earlier in the twentieth century that enforced social segregation and isolation (Flynn and Lemay, 1999).
Although person-centered-planning moves away from deficit-based approaches, there are contrasts between this approach and social models of disability. The social models locate disability within the social realm and emphasize that structural and attitudinal factors need to change in order to reduce disabling effects. Person-centered planning appears to maintain a level of passivity by the disabled person since that person becomes the recipient of services with the intent of achieving a valued social role. Table 1 lists some key terms that illustrate contrasts between person-centered approaches and the social models of disability.

Table 1

*Comparison of person-centered and social model approaches*

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<thead>
<tr>
<th>Person-centered approaches</th>
<th>Socially contextualized approaches</th>
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<tbody>
<tr>
<td>Share ordinary place</td>
<td>Universal Design</td>
</tr>
<tr>
<td>Make choices</td>
<td>Empowerment</td>
</tr>
<tr>
<td>Develop abilities</td>
<td>Disability as a social and political problem</td>
</tr>
<tr>
<td>Have a valued social role</td>
<td>Develop disability identity and culture</td>
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<td>Relationships</td>
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Person-centered planning considers each person an individual capable of growth and development but it falls short in providing a pragmatic way of including all people, regardless of disability, into the social world and as the driving force in service provision (Flynn & Lemay, 1999). Person-centered planning promotes shared ordinary spaces but does not acknowledge accommodations that would benefit most people through universal design of common spaces.
Person-centered planning also promotes choice-making in regards to both mundane and life changing decisions but within the human service industry economic and political empowerment are diminished by perceived dependency and limitations within the system. There is also a failure to address attitudes, perceptions, and discourses that service providers bring from mainstream culture and it does not validate disability culture without relation to normative standards that determine what makes up a valued social role. These social roles are dependent on relationships with non-disabled people who from a social model perspective can act as allies in social justice.

Person-centered approaches, although well intended, carry a paternalistic quality in which the professional still holds the power, knowledge, and resources and the developmentally disabled person does not. The language of person-centered approaches contains elements of a social view of disability but in practice it can be misapplied and the disabled person continue to be acted upon by service providers, family members, and professionals within the limitations and regulations of program-based services (Holburn and Vietze, 1998). It also assumes that the culture and lifestyle of non-disabled people is the norm that disabled people should strive for.

Approaches to disability within the service industry contain the language of the dominant discourse despite elements that allude to disability as a contextualized experience situated in the social and cultural realm. Organizations in service provision have adopted policies that emphasize individuality, independence, community inclusion, and productivity through the practice of person-centered planning. However, somewhere between planning and implementation there is a policy-practice disconnect that enables institutional and pragmatic limitations to supersede individual choices (Antaki, Finlay, and Walton, 2007). The person is
defined as the center around which services are designed but there are multiple driving forces that act upon the person creating tension between individual agency and institutional expectations.

**Self-determination**

Person-centered planning and self-determination are two practices that are part of the local/service-driven narrative (Renzaglia et al., 2003). Person-centered planning is a way of achieving self-determination. Self-determination is a way of giving people control of their own lives. Self-determination within the service delivery system intends to transfer power in decision-making and service provision to disabled people who receive services.

Self-determination as a psychological attribute was an idea introduced during the 1940’s and is composed of attitudes, behaviors, and skills (Wong & Wong, 2008). A person demonstrates self-determination in various levels through “specific attitudes (i.e. psychological empowerment and self-realization) and abilities (i.e. behavioral autonomy and self-regulation) ...they categorize self-determined behaviors into twelve components, which include choice-making skills, goal-setting and attainment skills and independence” (p. 231). A person is an active psychological and behavioral agent embedded in a dynamic interplay with the environment. Self-determination is not only a trait but it has become a service modality and part of the discourse within the service delivery industry.

Although self-determination is described as a set of behaviors that are intrinsically driven, they can be taught and influenced by contextual factors (Wong & Wong, 2008). The attitude of service providers in residential settings, for instance, is an environmental factor that
can promote or inhibit self-determination activities. In their work, Wong and Wong (2008) attempted to foster positive attitudes towards self-determination and provide service providers with knowledge on how to create a supportive environment to maximize autonomy. However, a paternalistic approach that positioned service providers and professionals as knowing best persisted.

**Contesting Normal**

The enforcement of socially constructed ideas of normality becomes the driving force for services. Owren and Stenhammer (2013) looked at how providers’ perspectives affect services for autistic people. They found that although policies encourage respecting service users’ rights, service providers’ preconceptions of autism rely on neurotypical standards to determine services that are deemed appropriate or necessary. The authors included a case study of an autistic woman who enjoyed going on walks but spent what was described as a very long time looking at raindrops or standing in the wind. These behaviors were described as pathology, obsessive compulsive rituals. Service providers attempted to intervene as walks, based on non-autistic standards, consist of walking to a destination and then returning. Owren and Stenhammer (2013) describe this imposition of normalized behavioral standards as discriminatory.

Conformity to norms, as maintained by normalization-based theories, discredits a disabled identity and negates the social, political, and economic factors that produce and maintain disability. Scholars such as Michael Oliver contest the assertion that normalization was an emancipatory theory and challenges the claim that normalization forged the way from institutionalization to community-based living (Oliver, 1999). Through normalization,
disabled people are expected to resemble the average person and lifestyle in order to acquire a socially valued role. Post-modern capitalism asserts the same ideology that led to institutions but is now masked under euphemistic and paternalistic discourses that maintain the position and power differential between the professional and the disabled person (Oliver, 1999). Oliver explained, “in the world of late capitalism, the same people, albeit with different job titles and perhaps in plusher buildings, are doing the same things to disabled people although they may now be calling them doing a needs led assessment or producing a care plan in Britain. Elsewhere it may be called individual program planning, social brokerage, change agentry and the like. But the material fact remains, it is still the professional doing it, whatever it is called, to disabled people” (Oliver, 1999, p.6). Although in practices such as person-centered planning the service user is part of service development, the social appropriateness of behaviors and actions are maintained by non-disabled normative standards enforced by service providers.

By applying Marxist materialist theory to disability and the human service industry, Oliver (1999) explained that disability is a social category created by a political and economic worldview. The human service industry, according to Oliver’s application of Materialist theory, maintains the category of disability as created by social, political, and economic systems. As he explained:

The production of the category disability is no different from the production of motorcars and hamburgers. Each has an industry, whether it be the car, fast food or human service. Each industry has a workforce which has a vested interest in producing their product in particular ways and in exerting as much control over the process of production as possible.
The production of disability therefore is nothing more or less than a set of activities specifically geared towards producing a good—the category disability—supported by a range of political actions which create the conditions to allow these productive activities to take place and underpinned by a discourse which gives legitimacy to the whole enterprise. (Oliver, 1999, p.2)

Political and economic systems construct and maintain social categories, such as disabled. The interrelationship between the political and economic circumstances are determinants in the definition, response to, and ultimately the experience of disability as Albrecht (1992) discussed, “indeed the political economy of a community dictates, what debilitating health conditions will be produced, how and under what circumstances they will be defined, and ultimately who will receive the services” (p. 14). A capitalist society places the responsibility of disability within the individual as a failure of that person to produce economically to self-sufficiency which justifies social exclusion and intervention (Oliver, 1999). According to Oliver, this explains the success of institutions in capitalist systems, “it is repressive in that all those who either cannot or will not conform to the norms and discipline of capitalist society can be removed from it” (Oliver, 1999, p.4). Institutions represented the physical segregation of disabled people but cultural and attitudinal discriminatory practices, including deficit-based discourses, continue to segregate disabled people despite the physical integration within community settings. Perceptions and attitudes enacted through discourses, continue to act as non-physical barriers in the exclusion of disabled people within industries of service and society in general.
Discourses

Cultural discourse goes beyond words used and spoken. As Hugman (1991) described, “discourse is about more than language. Discourse is about the interplay between language and social relationships, in which some groups are able to achieve dominance for their interests in the way in which the world is defined and acted upon…Language is a central aspect of discourse through which power is reproduced and communicated” (p. 37). The way that disability is defined, where it is situated, and the way that it is spoken about can be consequential in its construction and maintenance.

Discourses are the languages or ways of speaking that compose cultural narratives. Narratives can be understood as occurring in multiple spaces. Carol Thomas (1999) identified ways of speaking of disability through ontological, public, and meta-narratives. She described ontological narratives as “produced through the interaction of the inter-subjective with social narratives (social narratives being both public narratives and metanarratives) in time and space” (Thomas, 1999, p. 50). Public narratives go beyond the individual narrative and are based on cultural ways of conceptualizing and describing a construct. As it relates to disability:

Public narratives of particular relevance would include: the personal tragedy story; medical narratives about abnormality, deformity, rehabilitation and adjustment; the shame of the imperfect body story…metanarratives of importance here are the grand narratives which underpin the disablist public narratives listed above, involving, as they do, the very demarcation of what it means to be impaired (the social construction of the
impairment), to be a whole or less than whole human being, and thus be an acceptable member of the community.” (Thomas, 1999, p.50)

The cultural narrative of disability speaks of disability as a personal tragedy that allows for social exclusion due to impairments. Narratives are the cultural stories told and discourses are the words within those stories.

Discourses also compose the local languages of what can be conceived as micro-cultures. Gee (1999) made a distinction between Discourse and discourse. Discourse, with a capital D, does not signify particular words but rather is a way of being within a group. Groups define and enact identities and activities that go beyond the use of words (Gee, 1999). The ways of being and ways of speaking within the human service industry can be thought of as a Discourse. Within this Discourse are discourses, the local languages, of service delivery. In this study, different discourses are examined, such as the cultural narrative, the local/service-driven language, and the discourses enacted in situated practices.

Materialist and Foucauldian theory define discourses as constructed by and constructive of the world. A post-structuralist understanding of discourse sees language as a system of meaning that is both constructed and constructs action (McKenzie, 2013). The normalization narrative is based on the normal/abnormal dichotomy that assumes the differences between the two are existent in some reality and not a product of socially constructed categories. As Oliver (1999) explained, “materialist approach to this world suggest, as does the French philosopher Foucault (1973), that the way we talk about the world and the way we experience it are inextricably linked—the names we give to things shapes our experience of them and our experience of things in the world influences the names we give to them” (p. 167). In reference to
the discourses of normalization, people are reduced to the binary of normal/abnormal, negating the dynamic and interactional process of development. A Foucauldian approach to disability discourses emphasizes the role of power relations that enforce certain behaviors and subordinate others (Tremain, 2006). Normalcy is imposed through attitudes that position the professional as the expert and give authority to their discourses. The professional position is situated in a historical context relevant to the disabled person in society.

Historically the disabled person has been cast outside of normalcy by religious, moral, or medical standpoints that discredit the person as a human being who is capable of effecting change in their life. Perhaps in a subtle way, disabled people continue to be seen as incapable of making decisions perpetuating a process of disablement. Disablement can be enacted in the lives of disabled people through interactions with service providers, as well as, through the regulatory systems that passively exclude them from the processes that determine their own developmental trajectory. The theories and approaches on disability enacted by service providers and the human service industry can be influential in the lives of disabled people who use services.

The following sections provide a closer look at the discursive traditions of two theoretical models of disability that are often juxtaposed due to their opposing views. Alternatives to these models are also discussed in an attempt to move away from a dichotomous approach and provide a more holistic, dynamic and situated, and contextualized view of disability. I also include a review of some government policies that provide insight to the general cultural understanding of disability.
Medical Model Discourses

Medical discourses on disability rely on narratives that are based on a deficit-based approach that conceptualizes people in terms of normalcy, personal tragedy, and paternalism that privileges the professional and clinical opinion (Davis, 2006b). The terminology used to define what it means to be a person is relative to the non-disabled body and this defines the disabled person as inherently deficient. From this perspective, disability is defined as a medical condition that results in personal tragedy and can only be overcome by approximating non-disabled people. From a medical standpoint some of the themes that compose the deficit narrative and define the language of disability are: the disabled person as abnormal and deficient, disability as personal tragedy that can be overcome, and discourses that position the professional as expert.

Normalcy and deficiency. From the medical model perspective, disability is equivalent to physical or psychological impairment, understood as deviation from the normal range of functioning. Thoughts and behaviors are prescribed according to normative and normal is the standard to be achieved. Deviations from the norm are labeled and treated as *maladaptive*, in need of repair, and are seen as intrinsic categories of inferiority that are situated within the person (Dunn, 2011).

The concept of normal originated from psychological statistics and has been socially applied. Average is the ideal that is striven for. The French statistician, Adolphe Quetelet, promoted the idea of ‘l’homme moyen,’ the average man as the standard (Davis, 2006a). When applied to people, *normal* carries a moral judgment where difference from the mean is assigned a value of less worthy and as Grue (2011) noted, “one such discourse is that of the
normal/abnormal, in which deviation from the statistical mean of human ability or appearance are constructed as monstrous or deeply pathological” (p.535). Deviations from the mean, however, carry different value judgments. For instance, when considering intelligence, as measured by standardized testing, an IQ of two standard deviations below normal is judged to be a, “disadvantageous state: a perceived personal tragedy of individual pathology” (Dunn, 2011, p.33). However, an IQ of two standard deviations above normal does not carry the same judgment of personal tragedy.

IQ as a marker of normative functioning and the idea that IQ scores are a valid measure of an actual, innate attribute contributes to the perception of developmentally disabled people as less capable. Research by Ferri, Connor, Solis, Valle, and Volpitta (2005) looked at the ways that four teachers with learning disabilities negotiated discourses in their understanding of learning disabilities. The findings showed that the use of cultural and professional discourses along with the lived experience of learning disability presented both internalization and resistance to dominant discourses. Cultural understandings of IQ scores as a measurement of normalcy is reflected in everyday interactions by teachers, service providers, and other professionals.

Cultural understandings of disability are relevant to attitudes towards people in practice. Research by Myers, Ager, Kerr, and Myles (1998), identified three major attitudes that mediate interactions. These attitudes include willingness to interact, lack of awareness, and wariness or hostility. Wariness or hostility is a factor in the disablement process and it is an attitude that is frequently observed according to the authors. In Yazbeck, McVilly, and Parmenter’s (2004) study, three questionnaires were used to assess the attitudes of people with varying degrees of familiarity with intellectually disabled people. Variables such as the gender, age, and education
levels of participants, as well as, prior contact with intellectually disabled people were predicted to affect the degree of positive attitudes. They expected to find that participants who were female, younger, higher educated, and had prior knowledge or contact with disabled people would hold more positive attitudes towards intellectually disabled people. Yazbeck, et al.’s (2004) work defined an attitude as, “a learned disposition or internal biasing mechanism that focuses a person’s attention and provides a framework within which he or she encodes experience and the guiding parameter for his or her behavior” (p.97). Attitudes are contingent upon cultural perceptions and are socially constructed. Their findings supported the prediction that women held more positive attitudes. Also, higher educational levels, contact—daily or weekly, also correlated with positive attitudes.

Perceptions and attitudes are consequential on the daily experiences and interactions between disabled people and professionals. Reynolds and Hitchcock (2014) found that professionals demonstrated attitudes that may be considered deficit-based. For instance, based upon prior research, Reynolds and Hitchcock (2014) developed an instrument that specifically measured teachers’ attitudes towards Adult Basic and Literacy Education and learning disabled students. From their survey they concluded that although Adult Basic and Literacy Education instructors had a positive attitude towards learning disabled students, they did not provide referrals for diagnostic assessments or services because of a perceived inability to financially cover the costs of these services. The educators' perception or misconception was directly consequential to students’ opportunities to access services (Reynolds & Hitchcock, 2014). Professionals’ perceptions and attitudes limit opportunities based on the perception of incapacity.
Some studies have found that psychiatrists and other professionals, who are positioned as experts, are reluctant to provide equitable services to disabled people based upon deficit-based conceptions of incapacity and paternalism. For instance, Werner and Stawski (2012) reviewed literature relevant to attitudes and training of psychiatrists and as they related to developmentally disabled people with mental health needs. One of the studies in their review, Edwards et al. (2007), showed that 58% of Australian psychiatrists who participated, did not want to provide treatment to intellectually disabled adults (Werner & Stawski, 2012, p. 298). Further, Kuntz et al. (2003) assessed four areas: empowerment, similarity, exclusion, and sheltering, through the Community Living Attitudes Scale. The scale was administered to psychiatry residents in Canada. The researchers found that female psychiatry residents achieved higher scores on the similarity and sheltering subscales whereas men scored higher on the exclusion subscale. Similarity was defined as the perception that intellectually disabled people are like oneself, sheltering as the view that they need protecting, and exclusion as the inclination to exclude disabled people from the community. Overall, Kuntz et al. (2003) found that psychiatry residents, in their study, who achieved higher scores on the similarity subscale showed positive attitudes in empowerment, sheltering, and exclusion. The researchers suggested that training and education that promote similarity and commonality with intellectually disabled people may change attitudes. Similarly, Werner and Stawski (2012) argued that training that would increase understanding of disability can reduce negative attitudes (p. 302). Negative attitudes promote otherness when differences are compared to predetermined norms.

Research shows that normative functioning is a relational concept that has subsequently created a category of other that is used to define disabled people. McVittie, Goodall, and
McKinlay (2008) looked at ways that learning disabled people discursively negotiated their abilities and disabilities in relation to others. The findings show that relative ability is utilized by learning disabled participants as they compared themselves to others that they perceived as more severely impaired (McVittie, Goodall, & McKinlay 2008). Participants categorized more severely impaired people as others, similar to the use of normal by non-disabled people. Normal is part of the language of the medical model that situates disability within the person and creates the category of other.

Language and cultural discourses are enacted in professional descriptions of disabled people. The work of Goodley and Runswick-Cole (2011) tells the story of Rosie, an autistic child, from various discursive traditions including: the individual (medical), social, and sociocultural. The individual—the autistic canon—situates disability inside Rosie and is highly descriptive of what are characterized as innate deficiencies. It talks of Rosie’s development in comparison to non-autistic children and defines her and her family as existing outside of normalcy. This also alludes to the idea that the entire family feels stigmatized when the label of disabled is assigned to one member. Rosie’s behaviors and who she is as a person are seen through a lens of pathology. Similarly, Linton (1998) wrote, “the medicalization of disability casts human variation as deviance from the norm, as pathological condition, as deficit, and significantly, as an individual burden and personal tragedy” (p. 11). Living outside of normalcy comes to represent a tragic existence.

**Personal tragedy.** When disability is conceptualized as outside the norm, it is seen and described as a personal tragedy because there is something wrong with the person who carries the label. The person is rendered a tragic victim of her own body or mind. The view of disability
as a personal tragedy results in a paternalistic approach through which disabled people are seen as incapable and in need of care. The person is described as *suffering from* or *afflicted by* their disability. For instance, people who use wheelchairs are often described as *wheelchair bound* (Linton, 1998). Wheelchairs provide mobility but yet the dominant discourse describes wheelchairs as something the person is bound to. Discourse conveys a cultural message and as Ferri et al. (2005) stated, “language shapes and is shaped by the ideological assumptions held within a particular social structure” (p. 66). When this cultural message focuses on deficiency, people are portrayed as *having something wrong*. In Ferri and colleagues’ (2005) work, a participant described a teacher’s failure to recognize that there is something *wrong* with a boy with a learning disability. The participant stated, “you have to find out what’s wrong with them before you label them” (Ferri et al., 2005, p. 72). Assumptions and inferences are made about a person when they are seen as deficient.

As a corrective measure for personal deficiency, as is further assumed, it is up to the person to *overcome* their disability and achieve a more able-body. If this occurs, the person then achieves the status of disabled hero or *supercrip* and achieves this *despite* their disability (Amit, 2004). The term, *crip*, is a word that has been reclaimed by the disabled community. It is considered an insider term with the intent of shocking outsiders and creating identification with the in-group (Dunn, 2015). *Supercrip*, however, is a contradictory term as the status of *supercrip* is in itself disabling (Amit, 2004). A person is only a *supercrip* when she does things that resemble what a non-disabled person does; therefore, validating normalization. *Overcoming* disability negates the notion of disabled as a valid identity without an implicit need for comparison and reference to the non-disabled standard. As Urrieta (2007) wrote, “identity is
therefore relational” (p.118). Being non-disabled is the ideal and for a disabled person the impairment becomes the defining feature of who they are. From this perspective, there is a need to remediate disability by approximating a non-disabled person.

Attempts to approximate non-disabled people is thought of as occurring through overcoming disability. However, stories on overcoming often include a non-disabled person saving the disabled person from their disability. Ferri et. al. (2005) wrote, “the conventions of disability scripts often focus on stories of overcoming through individual struggle, cure, and rehabilitation, often with the assistance of a non-disabled character” (p.63). The disabled person is dependent and reliant on non-disabled people, often a professional, in attempts to assimilate normative functioning.

**Professional discourses.** The discourse of the professional is still riddled with words that culturally have been identified as oppressive (Linton, 1998). Stamou and Padeliadu (2009) interviewed teacher candidates and noted that traditional, medicalized, discourses accounted for more than half of participants' discourses during their study. The teacher candidates they interviewed drew upon both medical and social discourses even though their training emphasized social perspectives of disability. Despite their training, the teacher candidates continued to use the language of the medical model (Stamou & Padeliadu, 2009). Although trained within the social model perspective, reliance on deficit-based attitudes continued to tacitly persist and as Robertson (2010) observed, “yet when professionals discuss the challenges experienced by autistic people and people with other disabilities, societal stigma and attitudinal barriers rarely top the list. Many professionals tend to focus their efforts on functional tasks at the expense of focusing on the social climate surrounding disability populations. They may not be trained to
consider how social-cultural norms and perspectives create barriers in everyday life for people with disabilities” (n.p.). Socially oriented, holistic approaches are not readily enacted in everyday service provision and practices.

Particular terms within medical and professional discourses on disability are rather blatant in their significance. The word *retarded*, for instance, continued to be the clinical term used to describe intellectual disability in the Diagnostic and Statistical Manual IV (APA, 2000) but was replaced with intellectual disability in the Diagnostic and Statistical Manual V revision in 2013 (APA, 2013). Retardation was measured by degrees and represented a quantification of deficiencies. Although retardation was a diagnostic classifier until 2013, a lay campaign emerged online in 2007 with the goal of erasing the word *retarded* from public discourse (The R-word, 2007).

The lexicon of disability is emergent and continues to evolve with particular words moving into disfavor. Words such as *handicap, cripple, or invalid*, which were once part of the cultural narrative on disability, are no longer part of professional discourse (Charlton, 2000). On the other hand, words such as *patient, client, population, and consumer* continue to be used to describe disabled people by medical and social service professionals. Patient, client, and population overtly claim sickness and otherness. Developmentally disabled people were, until recently, referred to as consumers—within the service delivery system—because they use or receive support services. Consumer was intended to denote that support services were products that the person was purchasing (McLaughlin, 2007). Consumer, however, has a far subtler and insidious connotation. According to Merriam-Webster’s dictionary, *consumer* is defined as “one that utilizes economic goods; an organism requiring complex organic compounds for food which
it obtains by preying on other organisms or by eating particles of organic matter.” The opposite of a consumer is a producer. The reference of someone with a disability as a consumer can imply this person drains resources and is unable to contribute. According to Materialist Theory, disability is a product of our sociocultural and economic history (Oliver, 1999). A person is valued for their ability to financially contribute and when a person is seen as unable to fulfill that requirement, they are deemed a burden to the system; therefore, someone who consumes depletes resources and fails to contribute. Despite the implicit meanings, the term consumer remains a part of the human service lexicon.

As a reaction to what Linton (1998) described as nasty words, alternative nice words, have become part of the acceptable lexicon. These alternative words attempt to change the value judgment placed on disabled people but they do so in a paternalistic way that serves to disempower. Special, for instance, permeates professional and cultural discourses. In educational settings, special is the label used to identify disabled children, with expressions such as special education or special needs. Special is defined as something that is superior to the ordinary; however, Linton (1998) described that “special can be understood only as a euphemistic formulation obscuring the reality that neither the children nor the education are considered desirable and they are not thought to surpass what is common” (p.15). Linton (1998) saw special as a cultural reaction formation to a group of children that are undesirable so labeling them special serves to assuage the unconscious discomfort and cultural anxiety towards them. Similarly, differently-abled is another term that attempted to minimize the traditional emphasis on deficiency; however, differently-abled accentuates the position of otherness experienced by disabled people and perpetuates a dichotomy of us and them (Wendell, 2006). Differently-abled
connotes that there is a specific way of being and all other ways are different from that norm. Wendell (2006) equates this term to calling a racial minority *differently colored* or a woman *differently gendered*.

Words used to describe, label, and diagnose people are consequential in the positioning of service providers in relation to disabled people who use services. To remediate the effects of disability, educational and therapeutic interventions are legitimized. When disability is located exclusively in the body, it promotes a power relation between the professional as expert and the disabled person as a passive recipient. From this perspective, it is easy to disqualify the thoughts, opinions, and experiences of people with disabilities since “the knowledge of the medical profession has been privileged and is used to maintain the social position of the diagnosed” (Linton, 1998, p.76). Social exclusion and restrictions are imposed by experts in the best interest of the person. When people are not seen as unique individuals with thoughts, feelings and capabilities, they are defined through diagnoses within a classification system of incapacity and can be spoken of through a lexicon of deficiency.

The position of professional as expert, allows for the observation, study, and classification of people and their behaviors. Disabled people are objectified under the surveillance of the professional (Broberg, 2011). Broberg (2011) describes how parents of intellectually disabled children also fall under the *clinical gaze* that disempowers the family under the watch of the professionals who are positioned as the experts. Parents, in turn, change their behaviors in order to resemble the expectation of the professional. Professional discourses serve the purpose of maintaining an authoritative paradigm that maintains the position of disabled people and their families relative to professionals intended to provide services and
support. The clinical gaze is an enactment of this positioning. Treatment is justified as people are reduced to diagnoses and this allows professionals to act upon them. Medicalized discourses position the professional as expert and portray the disabled person as a passive recipient that can be acted upon through curative and normalizing interventions. Once diagnosed and labeled, disability becomes the primary identity marker and a person’s actions are interpreted through the lens of pathology. The labels that are used to treat and change people justify the professionals’ power over the lives of disabled people. When this occurs, the professional is in the business of “person-fixing rather than context changing” (Linton, 1998, p.6). The disabled person has to change to fit the prescribed notion of normalcy.

Although disability as a category of inferiority is maintained by cultural practices and discourses, counter narratives and alternative perspectives have emerged that challenge these views. The view that disabled people are deficient is challenged by social activism, through disability rights and self-advocacy movements, that redefine disability as a cultural minority and difference is seen as an aspect of human diversity. Disability as a disadvantage emerges through a contextualized disabling process that creates and maintains it.

Social Model Discourses

In contrast to the medical model, social models of disability do not view the person in isolation from the context and practices of her life. The social model introduced a distinction between impairment and disability. Impairment is a physical or psychological difference and disability is the social effects that result from structural and attitudinal barriers (Mitra, 2006). From this view, “society disables people with impairments” (Thomas, 2004, p. 571). These
consequences result in the restriction of activities because of the limitations imposed by the social context, not because of the actual impairment. The claim that disabled people are innately deficient is challenged by social models.  

Factors, such as language, in the social context play a role in disablement. Social factors interact to create disability and promote a process of disablement. Social models promote civil rights and social justice, not curative measures, to ameliorate conditions for disabled people, “the medical model focused on ‘personal defectology’...the social model has broadened in recent years to include a human rights component, which includes the right to health care, education, and social participation and it is also related with the quality of life model” (Jenaro et al., 2013, p. 497). The barriers in the social context that promote discrimination and oppression are considered the disabling factors and removal of those barriers is an imperative of the disability rights movement. The premise is that disability does not exist in a vacuum and society disables people. Further, the disability rights movement also attempts to change the language of disability. Shapiro (1994) wrote:

Language has been one of the first battlegrounds. Disabled people resent words that suggest they are sick, pitiful, childlike, dependent, or objects of admiration—words that, in effect, convey the imagery of poster children and supercrips…Disabled has become the usage of choice, replacing handicapped in recent years and becoming the first word to emerge by consensus from within the disability community itself. (p. 32-33)

Social model discourses resist medicalization and reposition disabled people as active agents in their own lives, as well as, experts in their self-definition. Terms that emphasize deficit
and passivity are resisted. Some terms are reclaimed and redefined. *Disabled*, for instance, has been reclaimed by the disability community as an identity that is valid and positive (Linton, 1998; Shapiro, 1994; Charlton, 2000). *Disabled person*, identity-first language, is preferred by many disability rights activists. Rocco and Delgado (2011) discuss the reclamation of the word disabled, “the earlier label *handicapped* has evolved to *people with disabilities* and to *disabled people* by those in the Disability Rights Movement” (p.5). *Disabled person* situates disability outside of the person whereas *person with disabilities* implies that disability is something the person owns (Rocco & Delgado, 2011). Disabled people are disabled by their social context, not by an intrinsic trait. This is exemplified in a reinterpretation of Goodley and Runswick-Cole’s (2011) Rosie, the post-modern autistic child, through the voice of the social model’s discursive tradition that situates disability within a socially oppressive and exclusive context in which education, transportation, and socialization are impeded by attitudinal and material barriers.

The interplay between dominant discourses of disability and a counter narrative of empowerment is enacted in situated practices. Disabled activists attempt to reclaim language but even a term such as *empower* contains latent reference to the power of dominant discourses. Jingree and Finlay (2008) explained that “the very term empower involves actions taken by those who hold power, while the recipient (or empowered) remains passive” (p.723). In their work, these researchers analyzed the discourses of support staff that work with learning disabled people in the United Kingdom. The themes that emerged presented a dichotomous discourse of autonomy versus practicality (Jingree & Finlay, 2008). The support staff distinguished between traditional and progressive approaches towards service-users by differentiating between the attitudes *old* and *new* staff members held. *Old* staff members provided less autonomy to service
users because of a perceived lack of capability. New staff members attempted to provide autonomy but were often constricted by institutional limitations and practicalities. Autonomy, in practice, is impeded by everyday pragmatics. The exercise of autonomy and independence were presented as something that was given by service providers.

The perception that disabled people are unable to act autonomously was also expressed by parents and family members of disabled people in three focus group sessions conducted by Jingree and Finlay (2012). Two groups consisted of seven and the other of four participants. Through discursive analysis of the focus group discussions Jingree and Finlay (2012) found that parents described government policies, such as self-determination that promote greater independence as “faddish, politically correct, and irresponsible” (p. 416). Parents positioned themselves as better able to make choices regarding preferences and services, despite policies that attempted to promote independence. They used hypothetical negative repercussions that could potentially happen if their children made choices that could jeopardize their health and safety. Their discussion constructed their family members as institutionalized and unable to cope with the regulatory changes that promote empowerment and independence (Jingree & Finlay, 2012). The disabled person was given ownership of the inability to make choices and cope with changes. The parents or caregivers’ approaches, in this instance, enacted deficit-based discourses that constructed their family members as lacking the capability to live up to government policies that they perceived as unrealistic, politically correct, and out of touch with everyday life. Policies such as person-centered planning acknowledge the risks that a person may incur but person-centered planning also prescribes an individualized approach to measure risk versus ability to
make choices, known as dignity of risk ("Risks and safeguards,” 2014). Potential risks can become prohibitive in participation in what are otherwise ordinary activities and experiences.

Within the human service system, there is a duty of care that can be in contention with dignity of risk. Service providing organizations are charged with the health and safety of people who use their services but mandates also promote self-determination and autonomy. The risk of overprotection and denial of autonomy are in tension with legal concerns regarding liability and consent. In New York, under Article 17-A Guardianship, parents of people who are “mentally retarded or developmentally disabled” can apply for legal guardianship which entitles parents to make financial and healthcare decisions ("Guardianship of a developmentally disabled people,” 2015). Parental choice and concerns of liability of the service providing organization may act as barriers in promoting autonomy for disabled people.

The social context creates barriers to participation. Unlike deficit-based approaches, social models assert that disability is socially constructed. Disabled is a category that has been designated as outside of normalcy and has been constructed by the medical, psychological, and educational professions. Goodley and Runswick-Cole (2011) wrote, “promulgated by the bio-power of psychology, medicine and education—and their global reach—these diagnoses actually construct the very objects (‘the autistic child’) and subjects (‘the child with autism’) they seek to describe” (p.54). The way that we talk about disability not only perpetuates a deficit model, it is one of the elements in the construction of a deficit model.

Some theorists argue that disability itself is created by culture (McDermott & Varenne, 1995). McDermott and Varenne (1995) recounted the story of Martha’s Vineyard in which there
was no distinction between hearing and deaf people because everyone knew sign language. Deafness was not a disabling factor and as McDermott and Varenne (1995) described, “disabilities are less the property of persons than they are moments in a cultural focus” (p.323). Disability is created by culture and in Martha’s Vineyard deafness was not disabling due to full integration in the structural and social environments that made no distinction between people who could hear and deaf people. In this case, a community was forged without distinction between deaf and hearing people.

Deaf community and culture, however, has emerged in which being deaf and a user of sign language constitutes a linguistic minority, not a disability. According to Minarik and Lintner (2013) explained, “the capitalized word “Deaf” identifies this cultural alignment. Deafness becomes part of a larger shared historical context, a shared form of communication through American Sign Language, and a general way of life, as opposed to a term describing perceived challenges defined by the hearing community” (p.17). Deafness is not inherently disabling but becomes a disability through the impositions of hearing and speaking as normalized abilities.

**Autism Discourses**

In recent years, the cultural narrative on developmental disabilities has focused on the discussion of autism. Autism has become popularized in mainstream culture and according to Johnson (2013) there have been over 283,000 books published between the years of 2010 and 2012 with the word autism in the title. The cultural discourses that have arisen from the autism conversation are varied. The neurodiversity and cure movements represent two opposing
discourses on autism. These discourses speak differently on the definitions, etiologies, and approaches to autism.

Neurodiversity is a perspective accepted by some autistic self-advocates whereas discourses on cure attainment are more often part of the conversation of some parent-led organizations ("ASAN," 2012; Johnson, 2013). Awareness of neurodiversity may be relevant to a person's relation to autistic people. Using a survey to assess awareness and evaluation of autism and the neurodiversity movement by people with different relations to autism, Kapp et al. (2012) found that, "as expected, autistic people and friends of autistic people, but contrary to expectations not relatives of autistic people, were more likely to be aware of neurodiversity then people with no relation to autism" (p.5). Kapp et al. (2012) also found that autistic people were less interested in finding a cause and cure for autism. They described that, "awareness of neurodiversity and self-identification as autistic correspond with a deficit-as-difference conception of autism" (Kapp et al., 2012, p.8). Deficits are viewed as differences and do not need to be cured but rather adaptive skills can be acquired in order to live in a world that privileges non-autistic behaviors.

The language of neurodiversity involves the reclaimation of once medicalized labels, it opposes the language of illness, and it contests the images of incomplete personhood. Autism rights advocates have reclaimed labels that were once pejoratively used to define types of autism. For instance, Asperger's syndrome—a type of mild of autism often referred to as high functioning—has been reclaimed and some people choose to refer to themselves as Aspies (Getliff, 2010). Aspie, in particular, has become a term that signifies pride, not pathology. Aspies for Freedom is an autism rights group that organizes an annual Autism Pride Day.
In addition to reclaiming that language of autism, autism rights groups also oppose common cultural images: portrayals of autism as a disease that is an epidemic, as a tragic kidnapping of children, and as incomplete personhood represented by the puzzle piece. The language of autism as epidemic appears to be sparked by media reports on increased prevalence rates. The autism epidemic connotes disease and sickness as epidemic is defined as “an outbreak of disease that spreads quickly and affects many individuals at the same time” (“Epidemic,” 2014). Epidemic has been used to describe outbreaks of infectious diseases throughout history. Identification of autism as an epidemic has social and political significance as it is reiterated in the cultural narrative that autism is a disease that poses a threat and needs to be eliminated (Johnson, 2013).

The words used to describe autism are consequential in its cultural portrayal and the neurodiversity movement contests the representation of incomplete personhood. Sarrett (2011) looked at representations of autistic children in cultural images and in academic literature. She found that “images and articles of children with autism from the 1960’s and the early 2000’s in major news media and scientific literature highlight the persistence of themes of fragmentation and the imprisonment of children with autism” (Sarrett, 2011, p. 141). Autistic children are portrayed as incomplete, as represented by the puzzle piece imagery, and as prisoners of their own bodies and minds. The child is trapped, captive, and somewhere inside is a non-autistic child waiting to be rescued.

Autism is also personified as a thief of children and this portrayal alludes to imagery of changelings or substitute children in pre-modern folklore and it is also relevant to modern psychiatric models of bereavement of the expected child. According to Kras (2010), “the idea of
a child being kidnapped by a supernatural force, in this case autism, originates in the medieval belief in the changeling, ‘abnormal’ beings who were substituted for so-called normal children” (p. 8). Goodey and Stainton (2001) reviewed the changeling myth in which children were stolen by fairies, trolls, or other mythical creatures then replaced by substitute children. In their review, they discussed how modern psychology continues to perpetuate parental bereavement models of the normal child, they wrote, “parents are said to be ‘naturally’ shocked and to mourn the loss of the child they expected but have not had… the cure is for parents to grieve for the child they have not had, and thus to endow their self-evidently pathological family life with a spurious normality, through a multistage process of acceptance that the child they have is not normal” (Goodey & Stainton, 2001, p. 224). Just like the changeling, the child that should have been is missed and longed for while the child that is present is foreign and rejected.

A current portrayal of the embodiment of autism as a thief of children was seen in a series of public service advertisements by New York University’s Child Study Center. The advertisements depicted ransom notes directed at parents addressed from autism, Asperger’s Syndrome and other neurodevelopmental differences indicating that their children were held captive (Kras, 2010). This advertisement campaign perpetuated the idea that autistic children are prisoners and that somewhere within that child there is an idealized child without autism waiting to be rescued. Robertson (2010) described some common metaphors of autism, “as portrayals of autism as a partial or whole loss of personhood, representations of autism as a retreat into an empty fortress, characterizations of autistic people as locked inside a shell, and presentation of autistic people as victims kidnapped and held hostage by their disability” (p. 5). As a result of
self-advocacy activities, particularly by the Autism Self-Advocacy Network, the ransom advertisement campaign was discontinued.

Furthermore, the misconception of incomplete personhood creates a dichotomy of *us* and *them* and posits that autistic people as both fragmented and in turn the source of fragmentation. The autistic *other* is incomplete, missing parts that are inherently part of the human experience such as talking and socializing through normalized means. Similarly, Sarrett (2011), through her review on pictorial representations of autistic children, found that fragmentation was used to describe autistic children and it was also used to describe the perceived divisive effects of autism on families. She wrote, “people with autism are portrayed and perceived as not being ‘whole’ people, and autism is depicted as a tragedy that will break up a family and its individual members” (Sarrett, 2011, p. 145). One way that incomplete personhood is visually depicted is through the puzzle piece imagery used to represent autism.

Autism is often represented by the single puzzle piece or incomplete puzzle metaphors. The use of metaphors can be influential on perception and construction of thoughts. Landau and Keefer (2014), in their review of metaphoric framing, found that “metaphors pervading everyday communication uniquely shape how people think and feel about a host of important issues” (p. 463). A metaphor is a cognitive tool that facilitates in the understanding of an abstract or unfamiliar concept through a more familiar or concrete idea (Landau & Keefer, 2014). The use of a metaphor may “prompt people to transfer source knowledge to interpret a target” (Landau & Keefer, 2014, p. 465). In the case of the puzzle piece as a metaphor for autism, the imagery reinforces the idea of a mystery child who cannot be understood. Puzzle imagery has been adopted by parent organizations such as Autism Speaks. Self-advocacy groups, such as, Autistic
Rights Movement contest the idea of incomplete personhood and see autism as part of the self. Autistic advocates describe autism as part of who they are, not something that makes them incomplete (“ASAN”, 2010). This puzzle piece image perpetuates a deficit-based perspective through which an autistic person is portrayed as lacking key human features.

Landau and Keefer (2014) also discussed the affective quality of metaphors as they operate emotionally, not just at a cognitive level. In their review, they interpreted metaphors as activating cognitive maps and act as affective primers resulting in the transfer of both information and emotion from the metaphor to the target (Landau & Keefer, 2014). As it relates to autism, metaphoric framing includes the puzzle piece, words such as combat, epidemic, and affliction and these images and words serve to elicit emotions of emptiness and fear.

Contrary to the imagery of the incomplete autistic child, is the autistic child with savant or supernatural abilities. According to Hacking (2009) fiction-based writing on autism includes the genre of the autistic child with secret powers. Autism is glamorized as a hidden ability that surpasses ordinary human abilities, the autistic child is portrayed as “different but with strange gifts, sort of a super child” (Hacking, 2009, p. 513). Much like the supercrip, the portrayal of the autistic savant is analogous to the noble savage (Anders, 2012). The autistic savant is an exotic outsider who is the source of curiosity but still outside of society.

To remediate the effects of autism, some organizations promote biomedical causes and cures. The cure movement is primarily led by organizations, such as Cure Autism Now, Autism Speaks, and Defeat Autism Now! that advance the pursuit for a cure (Johnson, 2013). In response to these organizations’ stance on curing autism, the disparaging term curebie has
emerged among some autistic advocates to label people who are intent on finding a cure. Advocates perceive some parents’ desire to have a child that does not show autistic traits as a desire to have a completely different child (“ASAN”, 2010). Within the cure movement there are many theories on the etiology of autism. One such theory attempts to connect autism to vaccines.

Some research has tried to establish links between autism incidence and vaccines (Blake, Hoyme & Crotwell, 2013). The connection between vaccines and autism was proposed by Andrew Wakefield who reported that the MMR vaccine was responsible for intestinal inflammation that allowed certain amino acids to enter the bloodstream and subsequently affect brain development. This article was retracted by the journal The Lancet but yet the idea that vaccines can cause autism persists. Evidence-based, empirical research has failed to identify an environmental factor as the cause of autism.

An exclusively biomedical approach relates to the ways autism is spoken about. For instance, a controversial label for autistic children was introduced in a discussion by Dr. Boyd Haley in 2004 during which he used the term “mad child disease” to refer to autism (Seidel & Seidel, 2005). In his assessment, degrees of autism correspond to different levels of mercury toxicity. Aside from the use of mad and disease, this description draws comparison to mad cow disease; therefore, making a comparison of autistic children to sick animals. The view of autism through a biomedical lens justifies interventions that stand outside of conventional behavioral interventions including interventions as harmless as dietary restrictions to contentious interventions such as chelation therapy and hypobaric treatments (Johnson, 2013).
The actions of organizations with an emphasis on cures may have emerged as a reaction to early theories on autism that posited parenting styles as the cause of autistic traits. Leo Kanner, in 1943, studied eleven children that displayed autistic traits. From his studies he discussed the cause of autism and he wrote, “as for the all-important matter of etiology, the early development of the eleven children left no other choice than the assumption that they had come into the world with an innate disability to form the usual, biologically provided contact with people” (Kanner, 1971, p. 141). The child’s disposition resulted in the lack of connection with others. Bruno Bettelheim (1967), however, thought the cause of autism could be attributed to the mother and he described, “the mothers of autistic children are often descried as cold and rigid, if not also intellectual. Certainly they are not free-moving in the realms of emotions or at least not in relation to their autistic child. In their emotions, then, many of them are nearly as frozen, nearly as rigid when they deal with the child as was Harlow’s terrycloth mother” (p. 448). His description would propagate the idea of the refrigerator mother; the cold mother who does not communicate with, show adequate affection, or bond with her child.

The placement of blame on parents is diminished by biological causes as they remove the link to the parent as the reason for autism (Farrugia, 2009). In his work with parent support groups Farrugia (2009) found that “the support group that this sample was drawn from emphasizes a biogenetic etiology for ASD, assuming an innate, biological foundation for the behavior of children diagnosed as ‘on the spectrum’….Following diagnosis, they are able to reinterpret and medicalize the meaning of their children’s socially inappropriate and difficult behavior, allowing the articulation of an unspoiled subject position through the creative, agentic
use of medical discourse” (p. 1016). By enacting medical discourses, parents are able to manage stigma relevant to their parenting and to their child's behaviors.

*On the spectrum* is an expression used to reference autistic people. *On the spectrum* connotes *other* and assumes particular characteristics and traits. Autism as a spectrum disorder was theorized by Lorna Wing (1991) with an identification of a triad of impairments: social interaction, communication, and repetitive behaviors. According to Farrugia (2009) clinically “individuals constructed *on the spectrum* are most commonly diagnosed with either Autism, Asperger’s Syndrome, or Pervasive Developmental Disorder” (p.1012). In popular culture, however, on the spectrum signals eccentricity or quirkiness. Interests in numbers or physical ineptitude are used as indicators that a person may be mildly autistic or *on the spectrum* (Wallace, 2014).

Psychology labels autism as a disorder, not a variation, but viewing symptoms as differences can be influential in education and in service provision. Behaviors that are thought of as pathological justify interventions of forced normalization and compliance to established social standards. There are various behavioral interventions that vary in methodology and intended outcomes. Non-autistic children are seen as the norm that autistic children are trained to assimilate and approximate as non-autistic behaviors are the expectations. Autistic children are scrutinized, diagnosed, labeled, and subjected to interventions that normalize their behavior. Applied Behavioral Analysis, for instance, emphasizes the teaching and learning of normalized behaviors (Kapp et al., 2012, p.2). In opposition to decontextualized teaching methods used with autistic children, developmental and sociocultural models of learning promote, “cognitive skills, knowledge and behavior regulation, not simply through memorization of facts or actions, but
through our interactions in the social world where this knowledge has function and meaning” (Donnellan et al., 2010). Within a dynamic system, context cannot be discarded or reduced to singular variables of antecedent and consequence.

Neurodiversity asserts neurological differences but some theories in cognitive psychology postulate differences in brain functioning as deficits. Modularity theories are some of the theories used by cognitive and evolutionary psychologists to explain brain functioning. As a result of natural selection, humans have adapted cognitive modules that account for human behavior and cognition, “behavior in the present is generated by information-processing mechanisms that exist because they solved adaptive problems in the past—in the ancestral environments in which the human line evolved” (Cosmides & Tooby, 1997, p. 12). Further, Baron-Cohen (1995) proposed a theory of mind module. Theory of mind is a developmental capacity that emerges during early childhood through which children are able to understand that others have different beliefs, intentions and desires than they do (Premack & Woodruff, 1978). Baron-Cohen, however, proposed that children with autism fail at theory of mind abilities, regardless of age, because they lack the theory of mind module. He described that “mindreading has an innate, biological, modular basis” (Baron-Cohen, 1995, p. 12). Since social interaction and communication are characteristics that are seen in all human cultures, it is assumed that they are innate traits under modular control.

Autism discourses represent an intersection between medical and social models. Neurodiversity asserts biological origins in neurological differences. Neurological diversity should not privilege one and classify others as disordered. Situating autism exclusively within the person as a deficiency or illness or exclusively in the social, as the product of social barriers,
negates the lived experience and complexity of human diversity. Autism as a biologically-based difference becomes disability in a context designed for non-autistic people that favors normalized behaviors over adaptive skills.

Alternatives to the Medical and Social Models

The medical and social models both present inadequacies when defining the lived experience of disability from a holistic and dynamic viewpoint. The medical model is a reductionist approach that relies on biological or psychological causes situated within the person. This model speaks of disability as an individual deficiency that is hard-wired and a diagnosis becomes the defining characteristic of a person. Categories are fixed and immutable. From this perspective, disability is not fluid or dynamic; it is not situated in history, culture, or time. Medicalization fails to acknowledge the social barriers that create and perpetuate disability. In contrast to the medical model, social models situate disability in the social context and emphasize eliminating social barriers that maintain disabled people in an economically and socially disadvantaged position. Disabled is a relational term that only holds meaning when it is compared to the norm, non-disabled, and disability can be mitigated through political, economic, and social action. In the case of the medical model, the person is the victim of biological deficits and in the social model the person is subjected to society’s barriers. A rigid social perspective fails to recognize the subjective experiences of impairment from a phenomenological and experiential point of view. It does not take a holistic approach to the embodied experience of impairment or the dynamic interplay of biological, psychological, and social factors in an ongoing process of disablement. The disabled person is once again reduced to the recipient of forces that define and shape their lived experience.
Through a disablement process, the experience of disability is unique to each person and is different from other socially imposed identities. Some theorists that adhere to a social perspective recognize that disability is an experience that is different from other socially constructed categories. Tobin Siebers commented that although “disability looks socially constructed...strong constructionism either fails to account for the difficult physical realities faced by people with disabilities or presents their body in ways that are conventional, conformist, and unrecognizable to them” (Siebers, 2006, p. 175). For instance, some disabled people may experience chronic pain which Carol Thomas (1999) termed impairment effects. The experience of a physical disability is different from the experience of a psychological or intellectual disability so within the social category of disabled there is great variation. The term disability can encompass many different types of physical and psychological characteristics and this is particularly relevant when disability is studied as a process, an interaction between individual characteristics and a social context.

**Stigma**

One way individual characteristics interact with the social context is through the experience of stigma. Erving Goffman’s (1963) work defined stigma as an identity marker that is a departure from norm expectations and is laden with stereotyped beliefs. He differentiates between discrediting and discreditable stigma (Goffman, 1963). A physical disability that is apparent and overt, such as the use of a wheelchair or a physiological difference carries a discrediting stigma (Goffman, 1963; Wendell, 2006). The physical impairment is a symbol of shame that should be hidden from others, as Wendell (2006) described, “weakness, illness, rest and recovery, pain, death and the negative (de-valued) body are private, generally hidden, and
often neglected” (p.247). In an ableist society, disability is not intended to be seen nor heard but rather to be treated with medical and behavioral interventions in order to more closely resemble normative functioning. But yet the disabled person is unable to hide, or pass, a discrediting stigma. Other disabilities, such as intellectual disability carry a discreditable stigma. This is a hidden or unseen stigma but it can become discrediting if it is discovered (Goffman, 1963). A child with dyslexia is indistinguishable from a child without it. A child with Down syndrome, however, may have physical traits that make it apparent and the experiences of stigma are different for the dyslexic child and the child with Down syndrome. The labelled person can assume the identity designated by the stigma further isolating the person from society. Individual characteristics of the person and the way that the stigma is managed, in turn, become mediating factors in the disablement process.

Stigma is also experienced by family members of disabled people. Goffman (1963) described the courtesy stigma that is experienced by people associated with a stigmatized person. Research with parents of autistic children shows the contextualized experience and management of stigma through the use of medicalized discourse. David Farrugia (2009) described the parental experience of stigma as “the influence that this has on parents’ construction of biographical identity and negotiation of the social world have been described using the concept of courtesy stigma (Goffman 1963) to argue that parents of children diagnosed with an autism spectrum disorder must manage a spoiled social identity due to the stigmatizing nature of their child’s diagnosis” (p.1014). As described by Goffman (1963), courtesy stigma describes a spoiled social identity due to interpersonal ties with a stigmatized person.
The effect of a stigmatizing label is a factor in the complex and dynamic process that creates and maintains disablement. In her work, Adreinne Asch (2001) discussed the interaction between impairments and the environments they occur in. The disablement process is complex and consists of many variables that make the experience of disability unique to each person. Asch (2001) noted that within the community of disabled people there is great diversity and she theorized disability as occurring on a continuum not as a dichotomous concept of able/disabled.

**Functional Limitation Paradigm**

Disability can be theorized as a process that takes place between the person and the context. An example of this process was theorized by Saad Nagi’s functional limitation paradigm. Also known as the Nagi Model, the functional limitation paradigm distinguishes between four processes in disablement: active pathology, impairment, functional limitation, and disability (Nagi, 1965). An active pathology is a condition or event that results in a different type of functioning and it includes the body's response to it (Nagi, 1965). Active pathology can produce impairment. The impairment is the actual difference caused by active pathology. A functional limitation is a person’s inability to enact specific roles or perform an expected function, such as walking and talking due to the impairment (Nagi, 1965; Masala & Petretto, 2008; Pledger, 2003). The impairment alone does not limit function but becomes a limitation in interaction with specific roles. A disability is a person’s inability to perform a socially defined role, such as working or traveling (Masala & Petretto, 2008). Disability was then described by Nagi (1991) as, “an inability or limitation in performing socially defined roles and tasks expected of an individual within a sociocultural and physical environment” (p.315). Functional limitations situated in a social context produce disability (Masala & Petretto, 2008). In the Nagi model,
disablement is a dynamic process where disability is neither in the person nor in the context. It is rather the result of the interaction between the two with mediating factors. Verbrugge and Jette (1994) revised the Nagi Model and included sociocultural and personal factors. In their reassessment, disablement is not a fixed, linear process and they identified risk factors, internal and external, as mitigating variables in the course from active pathology to disability.

**Dewey's Democratic Pedagogy**

Deweyan theories on intellectual disability also broke down the binary definitions of disability and the dichotomy of medical versus social interpretations. Dewey’s theory on the cause of intellectual disability avoided “the extremes of a naturalistic essentialism that frames the biophysical or psychological constitution of the individual as a deterministic factor in human activity, on the one hand, and a radical social constructionism that overlooks individual growth, learning, and agency amid notions of overwhelming cultural constraint, on the other” (Dansforth, 2008, p.57). From this perspective, people engage in activities that are effective or ineffective and it is the goal of pedagogy to increase effective activities a person engages in. The purpose of an educator is to maximize the conditions that allow for the achievement of potential. As a child develops, the rate and trajectory of growth varies and it only becomes pathology when it is confronted with cultural expectation (Dewey, 1916; Dansforth, 2008). As Dansforth (2008) explained, “the child is defined as failing to be the person he or she should be” (p.59). Dewey goes beyond both medical and social models. From this perspective, “removal of barriers is one part of promoting growth as ordered richness. But the other part is the creation of social environments that mutually enrich all involved. The capacities of individuals form a set of variables that must be considered in the process. A capacity that may be a disadvantage in one
social context, may be quite useful in another” (Lekan, 2009, p. 223). Although Dewey’s theory contains elements of individual traits and characteristics, these traits are not inherently disabling but become disabling when deemed so by the social context.

Further, Dewey argued for social integration of disabled people because it is mutually beneficial to disabled and non-disabled people. Diversity is valuable and benefits everyone. Democracy, to Dewey, was not just about government but applicable to education and social processes that include a full integration of all people, as he described:

A democracy is more than a form of government; it is primarily a mode of associated living, of conjoint communicated experience. The extension in space for the number of individuals who participate in an interest so that each has to refer his own action to that of others, and to consider the action of others to give point and direction to his own, is equivalent to the breaking down of these barriers of class, race, and national territory which kept men from perceiving the full import of their activity. (Dewey, 1916, p. 87)

It can be argued that exclusion or segregation of disabled people in social and educational settings can be considered undemocratic by Dewey's standards. Everyone has traits and capabilities that are advantageous and can contribute to society. As Lekan (2009) summarized, “the Deweyan democratic ideal of growth requires rich social integration of individuals by finding ways to use their unique capacities to contribute to social groups…this means we need to focus on our unique capacities, and what would thwart or promote them in specific contexts” (p. 225). When capability, instead of deficiency, is maximized every member can contribute to and participate in social processes.
Theories on Human Development

Social processes and human activity are areas of theorizing in developmental psychology. The interactive nature of social exchanges and processes indicate a dynamic relation of mutual influences in the construction of development. Development as a contextualized process lends to social interaction as a leading activity. The social model of disability proposes that society disables people through social and environmental barriers. Vygotsky, however, proposes that the disability arises from the social interactions disabled children experience and participate in that are consequential in the acquisition of higher psychological functions through culture (Vygotsky, 1993).

Cultural-Historical Psychology

Lev Vygotsky's work is based on the socially interactive processes of individual development during which human activity transforms the person and society. Vygotsky’s theories inform pedagogy and ways of learning from a developmental approach. From this perspective, children develop through participation in cultural communities. Vygotsky emphasized the social source of development (Vygotsky, 1993).

Vygotsky's cultural-historical or constructivist psychology proposed a perspective on the definition and experience of disability that is rooted in the social context. Vygotsky proposed that developmental disability is development that occurs differently and it should not be thought of as a lesser form. He wrote, “a child whose development is impeded by a defect is not simply a child less developed than his peers but is a child who has developed differently” (Vygotsky, 1993, p.30). When a person with impairments is confronted and conflicted by the societal context then disability arises through social interaction (Gindis, 1995b).
Vygotsky proposed a model of disontogenesis that made a distinction between a primary and a secondary defect (Gindis, 1995a; Kozulin & Gindis, 2007). The primary defect, to use the language of the time, is the actual impairment. The secondary defect is the social consequences of the primary defect. Therefore, impairment becomes disabling when the person encounters a social environment through interaction. Disontogenesis is based on Vygotsky’s Genetic Law of Cultural Development that posited that development, in general, occurs on two planes. Vygotsky highlighted the primacy of social interactions in development and asserted that development of higher psychological functions occurs twice: first interpersonally and then intrapersonally (Vygotsky, 1978). Development is a qualitative process of transformations that occurs through socially meaningful activities and Vygotsky referred to these interactions as interpsychological as they occur socially between people (Wertsch, 2007). These interpsychological processes are then internalized, transformed, and are reconstructed as intrapsychological processes (Vygotsky, 1978). Vygotsky’s social constructivist perspective grounds development in interindividual, social interactions, that become intraindividual processes. To Vygotsky, development was a complex process that is rooted in the social activities between children and adults.

The relationship between the individual and the social is dynamic so that one transforms the other and in turn is transformed by the other in a constant exchange. According to Vygotsky, there are two types of development that occur: natural and cultural (Kozulin & Gindis, 2007). Natural development involves “immediate” expressions or forms of abilities such as attention, memory, and imitative behaviors. Cultural development, the higher psychological functions, involves the use of symbolic tools that are used to mediate behavior. These psychological tools, language for instance, are appropriated through social interaction (Vygotsky, 1978).
Effects of disablement can be mediated through the acquisition of cultural tools and higher psychological functions. Vygotsky believed that “the most efficient compensation for the loss or weakness of natural functions could be achieved through the development of higher psychological functions” (Kozulin & Gindis, 2007, p. 342). The acquisition of culture serves as a compensatory strategy for impairment; however, many individuals with developmental disabilities are often deprived from full inclusion in sociocultural experiences and activities. For instance, the misperception that people with intellectual disabilities, autism, or other developmental disabilities are unable to learn leads to limitations in communicative engagement and perpetuation of infantilized interactions.

From Deweyan and Vygotskian psychology, human functioning is theorized as relational and person or context cannot be studied in isolation. Similarly, disability is a process—an interaction between the person and the context, not a static category. A person is embedded in the social environment and explanations that are exclusively biological or exclusively social neglect the effects of all the components that combine in different ways to create an individual person (Thelen, 2005). The experience of disability is not only socially situated but it is historically evolving. Pledger (2006) wrote, “historically, disability measures and definitions have varied in accordance with the understanding of disability and with social and cultural changes” (p.279). The category and the lived experience of disability are fluid and dynamic.

**Developmental Contextualism**

Disability is a human experience that is seen through many lenses and spoken of in many voices. Theoretical models of disability and their discourses, provide an understanding of disability that goes beyond the dichotomy of individual and society. The medical and social
models of disability present two opposing ends of the individual/society dichotomy by situating disability within the individual or within the social context. However, a more dynamic and holistic view speaks of a disablement process that is three-dimensional and involves the individual, the social, and the interaction between the two. Disability is not a fixed, immutable category but a dynamic process that is mediated by many factors and it cannot be defined or reduced to a uniform experience or classification.

Development in general can be seen as occurring through dynamic interaction between the person and multiple contexts. Development is probabilistic, not determined by genes or internal structures, or by social influences alone (Thelen, 2005). According to dynamic systems theory, human behavior is complex, shows continuity in time and shows dynamic stability. Firstly, behavior is complex because it is the “product of many interacting parts that work together to produce a coherent pattern under particular tasks, social and environmental constraints” (Thelen, 2005, p. 261). Behaviors arise from these components but development of behavior can occur via multiple pathways with similar outcomes. Secondly, dynamic systems are continuous in time because experiences from the past, present, and future are dependent upon one another. Behaviors are dependent on experiences that create patterns. The patterns of behaviors are all time-dependent, so the past, present and future are in active interaction and define and change one another (Thelen, 2005). Lastly, behaviors show dynamic stability so different patterns of behaviors may show different stability or flexibility. The person and the context are mutually interactive and small changes can lead to large consequences (Thelen, 2005). The embodied and the contextual experiences of each person presents an individual experience. The specific impairment, the person’s corporeal experience, the physical, social,
political, historical, and economic contexts are factors in the process of individual disablement and creation of the larger category of disability.

Dynamic systems theory defines development as the mutual and continuous interaction of all levels of the system from the molecular to the cultural (Smith & Thelen, 1993). Just as non-disabled people, developmentally disabled people develop through and are part of dynamic systems with multiple factors that contribute to who they are and what they do. These multiple factors create multiple pathways for development with various outcomes; therefore, a diagnostic label is not predictive of future outcome.

Although some developmental disabilities are biologically based, biology, including genes, and the environment are constantly changing (Gottlieb, 2003). Lickliter and Honeycutt (2003) describe the system as “gene-in-a-cell-in-an-organism-in-an-environment” (p. 828). Therefore, genes are neither fixed nor immutable. Additionally, the organism and the environment also change and develop through mutual processes. Human behavior, for instance, whether adaptive or maladaptive, is the result of the constant flux in the system. What are labeled as maladaptive behaviors may be different pathways to the same outcome. A child that acquires spoken language may ask for a desired item, whereas a child who does not communicate verbally may pull an adult’s arm to attain the desired item.

Disabilities are an unpredictable outcome of multiple factors. Biology and environment are but two components of a greater system. Many other factors contribute to the definition, experiences, and outcomes of disability. Parental expectations, social attitudes, professional
interventions, cultural attitudes, and discourses are some of the factors that designate people as disabled within processes of disablement or enablement.

**Policies and Legislation**

The ways that disability is theorized are consequential beyond everyday interactions and situated practices. Legislation is often a reflection of the cultural sentiment of the time. Policies and laws are consequential in the definitions and the implications for disabled people. Legislation can affect everyday experiences and enact processes that disable or enable.

**International Classification of Functioning**

Mediating factors between a person’s characteristics and the environment can be disabling but they can also be enabling. The World Health Organization’s International Classification of Functioning, Disability, and Health takes the disablement process and adds its counterpart the enablement process (Masala & Pettreto, 2008). Disablement and enablement are dynamic, not linear, so there is a bidirectional relation between factors. Unlike other theoretical models, the International Classification of Functioning, Disability, and Health uses the word health and describes disability as a “dynamic interaction between the health condition and contextual factors” (“International classification of functioning,” 2014). Health consists of three levels—the body, the individual, and society. Health levels have corresponding domains of functioning: body functions and structures, activity, and participation (“International classification of functioning,” 2014). The domains of functioning are associated with levels of disability: impairments, limitations, and restrictions.
The International Classification of Functioning, Disability, and Health describes disability as occurring between individual activity, participation, limitations, and restrictions (Pledger, 2003). A person’s ability to participate in activities occurs within an environmental context that includes physical, social, and attitudinal factors (Masala & Petretto, 2008). Just as the environmental and contextual factors can disable a person, it can provide the supports to maximize a person’s functioning (Pledger, 2003). The World Health Organization’s International Classification of Functioning, Disability, and Health offers an “integrated biopsychosocial model of human functioning and disability” (McKenzie, 2013, p. 371). This model underscores the relevance of environmental factors that promote a process of disablement and recognizes that impairment is still biological in origin (McKenzie, 2013). Language and discourses are considered contextual factors that affect the experience of disability, “the language that non-disabled people (e.g., professionals, family members, friends, strangers) use to refer to disability and people with disabilities constitutes an environmental factor, one that is often attitudinal or even institutional” (Dunn, 2015, p. 260). The ways that disability is spoken about is acknowledged as consequential.

**Americans with Disabilities Act**

The disablement/enablement processes and the shifting discourses on disability are influenced by policy and legal mandates that have practical applications that affect everyday experience. Courts and politicians decide the definitions of disability and enact factors that can promote ability over disability as a reflection of cultural sentiments of the time (Gordon & Keiser, 2000). The Americans with Disabilities Act of 1990, for instance, provided a legal definition that differed from clinical definitions of disability. The Americans with Disabilities Act
introduced the language of reasonable accommodation and substantial limitation. According to the Americans with Disabilities Act, impairment is distinguished from disability by three criteria: a disability substantially limits a life activity, there is a record or documentation of the disabling impairment, and others regard the person as having the impairment. Disability does not equate a medical or psychiatric diagnosis under the Americans with Disabilities Act; it is a relative experience that results from a disabling process embedded in physical and social environments. However, disability and substantial limitation are defined in relation to normative functioning. The Americans with Disabilities Act’s approach to limitation of participation in activities is relative to activities that are typical of the average person. Some activities are considered normative and failure to engage in those activities implies disability.

The Americans with Disabilities Act asserted a socially interactive approach to its definition of disability and the disablement process, similar to the Nagi model and the International Classification of Functioning, Disability, and Health. To remediate disablement, the Americans with Disabilities Act introduced reasonable accommodations which are “task-specific and are meant to eliminate or reduce the impact of impairment on a particular activity” (Gordon & Keiser, 2000, p. 16). Reasonable accommodations are environmental modifications that can limit the impact of impairments by allowing a person to participate in ordinary activities. These accommodations are specific to tasks but also specific to person and environment. The Americans with Disabilities Act not only safeguarded civil rights, it also redefined disability as a part of a multidimensional process and consequently resulted in real changes in the lives of disabled people. Subsequently, impairments were distinguished from one another and it was recognized that individualized accommodations were required to reduce imposed limitations.
A distinction can be drawn in the differential experience of disability and benefit from a reasonable accommodation depending on impairment, person, history, and context. Although sidewalk curb cuts and accessible parking spaces are often attributed to the Americans with Disabilities Act, these accommodations are most beneficial to people with mobility impairments (Gordon & Keiser, 2000). People with intellectual disabilities, on the other hand, require different types of accommodations.

**Combat Autism Act**

The Americans with Disabilities Act’s approach to disability is not shared by more current legislation that exclusively identified autism, The Combat Autism Act enacted in 2006 (Olmstead, 2006). This act provided funding for autism research, treatment, intervention, and education (“Combat Autism Now”, 2006). The act appropriated $900 million towards biomedical research and treatment and $45 million for research on environmental factors relating to autism (Olmstead, 2006). Funds were appropriated in attempts to find causes and treatments with the implication that autism should be cured. The consequence of locating autism within the medical realm as a disorder, prioritizes funding for research for cause determination and cure attainment (Kapp et al., 2012).

Parent led organizations such as Autism Speaks and Cure Autism Now praised Congress for declaring war against autism. The discourses of the Combat Autism Act included the language endorsed by those particular organizations that engage in discourses of illness and epidemic, as well as, military language to describe autism research. The co-founder of Cure Autism Now described the legislation as “a federal declaration of war on the epidemic of autism… it creates a Congressional mandated road map for a federal assault on autism” (“Combat
Autism Now,“ 2006). The act specifically targeted autism as a biological illness that needs to be
cured.

The Combat Autism Act situated autism inside the person and negated a person-context
interaction, which was noted in the Americans with Disabilities Act. The Combat Autism Act’s
language relied on medicalized definitions and military/war metaphors similar to Kennedy’s
Combat Mental Retardation Act during the 1960’s. The word combat, specifically, clearly stated
that autism is something that must be fought against. The Autistic Self-Advocacy Network made
a distinction between the language of the Combat Autism Act and other disability policies that
had a broader understanding of the etiology of disabilities (“ASAN,” 2011). The Autistic Self-
Advocacy Network described the language of the Combat Autism Act as offensive and out of
date with current viewpoints. The allocation of funds appropriated to autism research and
intervention is a clear indication that autism is viewed as a disorder, not a neurological
difference, that needs to be remediated. If the goal is to fight autism, what are the implications
for children and adults who are being fought against? The development of an autistic child, as
any other child, is produced by and embedded in dynamic systems the identification of biological
or environmental causes and treatments as the exclusive focus of attention and intervention
negates the complexity of human development.

In 2014, President Barack Obama signed the Autism Collaboration, Accountability,
Research, Education, and Support Act (AutismCARES) as a renewal and revision of the Combat
Autism Act (Diament, 2014). In addition to changing the name of the act to AutismCARES, the
revision provides greater support for autistic adolescents and adults. Prior to signing
AutismCARES, President Obama nominated Ari Ne’eman, the co-founder of the Autism Self-
Advocacy Network, to the National Council on Disability in 2009 despite opposition from parent organizations (“Many in autism community,” 2010). A letter published on the Age of Autism website tried to persuade President Obama against the nomination. The letter described Ari Ne’eman, as a high-functioning individual who promoted neurodiversity, an approach that in their view, “will not prevent the next generation from being afflicted” (“Many in autism community,” 2010). The description of Ne'eman as high-functioning exemplifies the dismissal of non-stereotypical traits. The dismissal of autism when a person displays behaviors seen as outside the capability of an autistic person parallels the labeling mundane behaviors as symptoms in order to reaffirm a diagnosis. Once an autism label is designated, particular behaviors are the expectation. Behaviors that are outside those parameters are used to invalidate an autistic identity.

In response to organizations, such as Autism Speaks, self-advocates and bloggers have expressed their dissent of the portrayal of children as sick or incomplete puzzles. These portrayals of autism as described as, “the consistent message put forth by Autism Speaks has been that autistic people are tragically defective burdens on society and that a child would be better off dead than autistic” (Kras, 2010, p.4). Instead of disorder, tragedy, or burden, some self-advocates promote neurological difference as a source of empowerment. Autism as biologically rooted reaffirms naturally occurring neurological diversity but autism as disabling is socially embedded in structural and attitudinal barriers. These barriers include discursive traditions that enact processes of disablement.

Perspectives and ways of speaking of autism, and developmental disabilities in general, are the focus of this study. Service providers in the human service industry engage in direct
interactions with developmentally disabled people and their conceptualizations and discourses can offer insight to everyday practices. Service providers can also serve the function of ally to disabled people by improving quality of life and negotiating effects of structural and attitudinal barriers. Consideration of the role of service providers and the effects of disablement inform the methods selected for this study.
CHAPTER 2

METHODOLOGICAL APPROACH

The methodological approach was informed by sociocultural theories on development, teaching and learning, and dialogue—guided by Vygotskian theory, Stetsenko’s Transformative Activist Stance (TAS), and Bakhtin’s theories on dialogue. Following the principles of sociocultural Vygotskian psychology, and Transformative Activist Stance (TAS) the methods selected were attempts at interactive collaboration of ideas between participants during which I was also actively engaged.

Zone of Proximal Development

In Vygotsky’s sociocultural psychology, psychological tools mediate social and individual thought and behavior, they serve to shape the mind, and in turn are shaped by the minds that use them (Vygotsky, 1978). Mediation is a central process in this theory, as it serves the function of connecting the individual and the social context. Tools are oriented to the social in order to effect change on the external world. The social context provides psychological tools, interpersonally and intergenerationally. Psychological tools are acquired through social interaction and do not spontaneously occur in isolation within the individual. Cultural mediation through the use of psychological tools allows the individual to effect change in the environment and to operate at a higher developmental level.

To Vygotsky, instruction leads development and the goal of teaching and learning is to help people become users of semiotic tools (Wertsch, 2007). Vygotsky’s theory on the zone of proximal development illustrated the interaction between the person and the social context. The
zone of proximal development posited that there is a difference between what a person is able to accomplish working in isolation and what a person can accomplish with guidance, scaffolding, from a more skilled peer (Vygotsky, 1978). Development occurs within social interactions during which a person works with a more capable peer to solve problems. When a person is engaged in this zone, the person is able to achieve beyond their current level of development.

Engagement in the zone of proximal development was demonstrated by Lapkin, Swain, and Psyllakis (2010) as they assessed the role of languaging with a resident in a long-term care facility. They defined languaging as, “the shaping and organizing of higher mental processes through language use mediates the zone of proximal development in the engagement of cognitive or affective activities” (Lapkin et al., 2010, p.478). In their study, they attempted to engage their participant not by simply visiting or talking to him but their “interventions were based on languaging, a cognitively demanding form of language use by the cared-for intended to mediate cognitive/affective functioning that afforded opportunities for agentive action, cognitive development, and affective engagement” (Lapkin et al., 2010, P. 479). The researcher engaged the participant in conversation and cognitive activities that were relevant to his interests prior to residing in the long-term facility. During the process, there was a co-construction of meaning and knowledge that resulted in a positive affective state for the participant, as evidenced by greater enthusiasm and interaction with others, particularly his spouse. This study demonstrated Vygotsky’s (1978) assertion that instruction leads development and learning occurs within the zone of proximal development.
**Transformative Activist Stance**

Further, Stetsenko (2010) discussed the idea of collaborative purposeful transformation through which teaching-learning and development do not occur through the transmission of information into a person’s head or through internal processes of thought removed from interaction and engagement. Collaborative purposeful transformation, rather, is rooted in social practice and is “mediated by cultural tools with each individual playing an indispensable role in carrying out these activities through the very process of contributing to them” (Stetsenko, 2010, p.7). The learner is not a passive recipient of information but rather is an active contributor to the creation of shared knowledge and to individual identity through engagement with the social environment, beyond bidirectional engagement. Transformative activist stance proposed that, “people come to know themselves and their world and ultimately come to be human in and through (not in addition to) the processes of collaboratively transforming their world in view of their goals and purposes” (Vianna, Hougaard, & Stetsenko, 2014, p. 62). By engaging one another people can effect change in the world, “the transformative ontology directly implies that people have to rely on *collective experiences* and *efforts* to bring about changes in the world through their practice” (Stetsenko, 2010, p.10). By sharing experiences through dialogue, individual thoughts and experiences become part of a collective awareness to promote a process of action and change.

The use of the focus group method, however, is an opportunity for collaboration through active engagement with and dialogue between participants and the researcher. Focus groups have become relevant to action research with disadvantaged social groups and have been used as a conscious-raising tool to foster social change, such as Paolo Friere’s dialogic method.
Paulo Friere’s banking model of pedagogy described traditional ways of teaching-learning as the deposit of knowledge and information from the teacher into the head of a student, much like a person would deposit money into a bank account (Freire, 2000). By collaborating with participants and relying on their perspectives and experiences, the banking model is avoided during this study.

**Bakhtin's Internal and External Dialogism**

In this study, narrative inquiry and focus group discussions are used to explore participants’ individual perspectives and their ideas in interaction with others, drawing from Mikhail Bakhtin’s theories on internal and external dialogism. In Bakhtin’s analysis, unlike Vygotsky, language is not a tool but rather it is “an essential condition for being in the world: life, itself is ontologically dialogic” (Mishra, 2015, p. 74). In this study, language and dialogue are seen as tools in making sense of experiences, constructing ideas, and effecting change. But language is also seen as constructed and constructive of self and others. Through dialogue people make meaning and Bakhtin described two types of dialogue: internal and external (Mishra, 2015).

Internal dialogue is situated in a socio-historical space and does not stand in isolation within the person. As Bakhtin (1984) noted, “in the process the word does not forget its own path and cannot completely free itself from the power of these concrete contexts into which it has entered. When a member of a speaking collective comes upon a word, it is not as a neutral word of language, not as a word free from the aspirations and evaluations of others, uninhabited by others' voices (p.202). Internal dialogue draws from the socio-historical context and it is also
multi-voiced. Dialogue consists of utterances and in Bakhtin’s theory, the utterance is the unit of meaning, it is a micro-speech act, and the utterance is embedded in the socio-historical context (Francis, 2012). An utterance indicates addressivity—it addresses someone and it anticipates a response (Mishra, 2015). The listener responds to the speaker’s utterance and within dialogue meaning is made (Weatherly Valle & Aponte, 2002).

The multiple voices in a dialogue create what Bakhtin referred to as heteroglossia (Mishra, 2015). When diverse voices are unified there is polyphony, “the centrifugal forces of heteroglossia, must be balanced by the centripetal impulse of a single consciousness in order for polyphony to subsist” (Mishra, 2015, p. 77). Discourses are shaped by centripetal and centrifugal forces and as Mishra (2015) described, “centripetal force works in uniting, homologizing, and monologizing the discourse. Centrifugal force works in diversifying, diffusing, and dialogizing the discourse” (p. 77). Multiple voices in both agreement and conflict create polyphony, “the simultaneously present and consecutively uttered plurality of independent and unmerged voices and consciousness” (Nikulin, 1998, p. 382). The interaction does not lead to an end point or to a resolution in polyphony, “its telos does not lie in a certain future point which may be achieved by consensus” (Nikulin, 1998, p. 394). There is not a goal or a correct answer to be achieved because dialogue does not have finality. Meaning is created through dialogue.

The purpose of both narrative inquiry and focus group discussion was to hear the multiple voices within and between participants through engagement and dialogic interaction. Guided by Bakhtin's theories on dialogism, qualitative methods were used to listen to participant's multiple voices both in narrative and then in interaction with others in a focus group. The narrative phase
offers insight to internal dialogue. Narrative inquiry was used to understand the thoughts, experiences, and discourses on developmental disabilities of service providers, direct support professionals in particular, within one particular non-profit organization. The focus group was intended to elicit external dialogue and promote collaboration through dialogue. As it relates to teaching and learning, people learn through dialogue, “truth is not born nor is it to be found inside the head of an individual person, it is born between people collectively searching for truth, in the process of their dialogic interaction (Bakhtin, 1984, p.110). The focus group was also intended to engage participants in the zone of proximal development. I attempted to promote engagement between participants and with me in order to understand their ways of theorizing and speaking of disability, and to introduce concepts of neurodiversity and disablement as they relate to situated practice.

**Narrative Inquiry**

Narrative inquiry as a research method is an effective tool in understanding everyday experiences and the enactment of cultural practices. Michael Quinn Patton (2001) described personal narratives as revealing of “cultural and social patterns through the lens of individual experiences” (p.115). Narratives disclose internal perceptions and attitudes that are rooted in larger cultural narratives. In this study narratives were also used to understand the lexicon, terminology, and discourses used by each participant individually.

Although narratives offer insight to participants’ points of view, these views are situated within a larger social context. Through narrative a person expresses and understands who they are and through narrative a person makes meaning of the world around them (Bruner 1990).
However, narrative accounts are mediated by and are reflective of social contexts (Gergen, 1994). For this reason, narrative from service providers are an expression of the way they make meaning of disability and the people they work with but their accounts are seen as situated within their societal contexts and practices. Service providers came into this field of work already embedded in a greater cultural context and then acquired the practices and local languages of this specific industry and organization. The practices and discourses of this organization a micro-culture with particular ways of doing and speaking.

The narratives in this study were used to gain insight to individual voices prior to the focus group discussion, without revealing information that would compromise confidentiality or anonymity. Analysis of narratives focused on the types of discourses used by participants, the perception of the disabled people they work with, and the way they view and define their role in the work that they do. From this perspective, “if you are truly interested in the subjective experience of the participants, it is their concerns rather than the researchers’ that must take center stage” (Auerbach & Silverstein, 2003, p. 33). My involvement during the individual interviews was limited to asking the interview questions in order to hear participants’ voices from their own perspectives.

Prior research informs discourses enacted by service providers. Carl Bachke (2012) conducted a research study that looked at discourses used by professionals in service provision in Norway. Using qualitative methods and a discourse-analytic approach, Bachke (2012) assessed the terms used by professionals. In this work there was discussion by participants on disabled people’s diagnoses but they also used terms such as patient/client, user/customer/citizen, and service receiver (Bachke, 2012, p. 61). The conclusions indicated that there was still uncertainty
as to what were appropriate terms due to lack of systemic changes establishing specific terminology and lexicon. Bachke (2012) also found that, in Norway, discourse is led by social constructionism which has been responsible for the removal of the word mental from labels and professional terminology, such as “feeble-minded, mental deficiency, or mental developmental disability” (Bachke, 2012, p. 71). Similar patterns are seen in the United States related to the removal of word *retardation* from clinical diagnoses.

Research other than that pertaining to service providers or professionals, relevant to developmental disabilities was also used to inform this study. For instance, Tom Billington (2006), collected narratives from autistic children with the assumption that the children were the experts on their own lives, instead of the more traditional model, which assumed that professionals were the experts. Similarly, Douglas Biklen (2000) gave voice to children with developmental disabilities through their narrative accounts. The focus of this work was not the children’s impairments but their opinions on school inclusion. From his work he deduced that school performance was contingent upon context, not disability.

A study conducted in the United Kingdom by Clare Connors and Kirsten Stalker (2003) looked at the ways children understood disability from the perspective of the disabled children and their siblings. Connor and Stalker (2003) used qualitative methods and elicited narratives to understand how children made sense of disability. The results indicated that children view their disability from a medical perspective but yet they described social barriers as the factors that exclude them from full community participation. Younger children did not see their impairment as disabling; however, older children became aware of their disability through their experiences with societal contexts that made them feel disabled.
Focus Group

The use of focus groups as a tool originated in market research but focus group research can be a useful method relevant to psychological processes, interpersonal interactions, and discourse analysis. Robert Merton and Patricia Kendall first used focus groups in sociological research in 1946 (Woodring, 2006). A focus group is defined as “a relatively planned discussion aimed at uncovering the range of perceptions surrounding a given topic, consisting of a small group of people sharing experiences deemed relevant to the research questions” (Woodring et al., 2006, p. 249). In this study, the focus group discussion was the space in which different voices and perspectives came into interactions.

According to Wilkinson (1999) focus groups generally consist of six to eight participants and are seldom larger than twelve. Similarly, Patton (2001) described typical focus groups consisting of six to ten participants. Informed by prior research, the goal for this study was to recruit a maximum of ten participants.

Participant recruitment was limited to direct support professionals with the assumption that when people share common experiences they are better able to engage one another and problem solve. The resultant participant group for this study was homogenous with various common traits. All participants were employed by the same non-profit organization and they worked directly with developmentally disabled people. Participants were recruited from one voluntary service provider as providers constitute a micro-culture of commonly shared experiences, training, policies, and practices. The purpose in the selection of a homogenous group was that it maximized the level of comfort particularly during the focus group discussion,
“focus group literature recommends adhering to the established procedure of assembling groups that share similar demographic characteristics such as race, gender, age, and class” (Woodring et al., 2006, p.250). The discussions were most relevant to people who met the inclusion criteria, “sampling for focus groups typically involves bringing together people of similar backgrounds and experiences to participate in a group interview about major issues that affect them” (Patton, 2001, p.236). Some participants were already acquainted or had working relationships prior to participation in this research study. Participation of people who know each other prior to entering the research setting may benefit focus group data as participants can use familiar people for social reference and validation of information (Wilkinson, 1999).

The focus group discussion was intended to bring multiple voices in an interaction through dialogue. During the focus group I introduced the concepts of neurodiversity, disablement. These ideas were then related to disability discourses and situated practices. These concepts were discussed in collaboration with and between participants.

Focus group method approximates a natural process of interacting and discussion through which many voices come together, possibly in conflict, without the expectation of resolution. Sue Wilkinson’s (1999) work on feminist research and focus groups discusses how this method avoids artificiality, decontextualization, and exploitation. Unlike experimental research, focus groups avoid artificiality by allowing participants to communicate and enact social processes in a way that naturally occurs outside of the research setting (Wilkinson, 1999). Focus groups recreate an everyday interactional setting. Dialogue naturally occurs between family and friends when discussing a topic so it is an activity that is familiar to most people. Although focus groups are not naturally occurring phenomenon because they are brought together for research purposes,
“the interactions that take place within focus groups are closer to everyday social processes than those afforded by most other research methods” (Wilkinson, 1999, p. 227). This allows the researcher to see group dynamics through interpersonal interactions. By engaging with others meaning is made. This engagement occurs in the context of a social encounter, “collective sense is made, meanings negotiated, and identities elaborated through the processes of social interaction between people” (Wilkinson, 1999, p. 224). Focus groups allow for the “co-construction of meaning and the elaboration of identities through interaction” (Wilkinson, 1999, p. 229). In a focus group a person negotiates identity through active engagement and makes meaning of their experience with others. The use of focus group data collection directly relates to understanding discourses, “the analytic emphasis is on the construction and negotiation of persons and events, the functions served by different discourses, and—for feminists—the ways in which social inequalities are produced and perpetuated through talk” (Wilkinson, 1999, p. 237). It is also relevant to understanding how service providers theorize disability, the people they work with, and their role in the work that they do.

Focus groups also shift the locus of power to the participants and away from the researcher therefore avoiding exploitation (Wilkinson, 1999). In a group setting, the researcher’s agenda and language become more difficult to impose as participants are actively engaged in interacting with one another instead of directly interacting with the researcher. Woodring, Foley, Santoro Rado, Brown and Hamner (2006) make a distinction between group interviews and group discussions when focus groups are used in qualitative research. The primary differences are the control that the moderator exerts and the group dynamics that emerge during interview or discussion sessions.
In the field of developmental disabilities, some studies have used focus groups to obtain data from service providers, developmentally disabled people, and family members. Jenaro, Vega, Flores, and Cruz (2013) conducted focus groups with service providers for intellectually disabled people. In their work Jenaro et al. (2013) reviewed various models on intellectual disabilities and they proposed that “models have implications both for understanding the underlying phenomena and for validating professional practices” (p. 490). The quality of life paradigm, for instance, has been influential in the development and implementation of person-centered planning and services (Jenaro et al., 2013). Quality of life encompasses areas such as “participation, leisure, self-care, domestic skills, education, and work” (Jenaro, et al., 2013, p. 490). The way that quality of life is incorporated into service providers’ interactions depends upon the cultural and social context and Jenaro et al., (2103) noted “normative needs depend on professional judgment but also vary with cultural context. Therefore, if we want to better understand what they consider important, service providers must be asked, what it is being done and which constraints they face in their daily practice” (p. 491). A better understanding of situated practices can be achieved through qualitative methods in order to hear service providers' voices.

Ward, Nichols, and Freedman (2013) used focus groups consisting of parents, self-advocates, and community support professionals to assess health care inequalities for people with intellectual and developmental disabilities. Ward et al. (2013) used grounded theory to analyze their data and the results showed that all three groups of participants perceived health care disparities across health care access, knowledge, communication, and quality. In everyday experiences these translate to a limited number of health care practitioners that provide services
to developmentally disable people resulting in accessibility difficulties. Encounters with health care professionals revealed negative attitudes and a lack of knowledge of developmentally disabled people that in turn limited communication and resulted in health care professionals talking to parents or community support professionals instead of the person.

The focus group approach for this study was guided by the pedagogical principles of sociocultural theory and transformative activist stance to understand disability discourses enacted in collaboration between participants and with me. During the focus group, neurodiversity and disablement were discussed. These ideas were related to web-based reading excerpts that served as mediating tools in their discussion.

The reading excerpts used during the focus group discussion focused on neurodiversity and disablement as a contextualized process that is enacted discursively in situated interactions. Excerpts on neurodiversity, used in this study, came from websites and blogs written by autism rights advocates. The internet has emerged a tool utilized by autistic people to relay their thoughts, experiences, and create communities (Davidson, 2008). Neurodiversity was selected as a topic of interest since it moves away from ways of thinking and talking about disability as deficiency. Neurodiversity can also be interpreted as an intersection between medical and social approaches, a representation of disablement as a process that is neither exclusively biological or social. Kapp et al. (2013) encourage awareness of neurodiversity, “learning about neurodiversity may serve as a turning point toward a more holistic conception of autism” (p.60). Introduction to neurodiversity offers an alternative perspective that defines autism as a naturally occurring difference, not a disorder.
The readings also included perspectives on the interactive process of disablement. Research on discourses and disablement have shown that the ways that disability is spoken about and conceptualized translates into real life limitations due to the attribution of impairment. Participants were referred to the publication Goodley, D. & Runswick-Cole, K. (2011) available online as this article provides an example of different ways of describing the same person from different perspectives.

Readings were selected that presented disability as a contextualized experience. An interactive approach in the understanding of disability may decrease limit setting and lowered expectations, therefore, altering the disablement process. As someone can be defined as having impairments, they can be defined as having competence. Capability or competence within an interactive enablement process is not an individual trait within the person, “competence is not seen as a property of the individual but a construction of contexts and participants—competence is both contextual and distributed across social actors. Thus the focus shifts from the inherent limitations of the individual to a continuous search for enabling contexts…competence is a collaborative product of social interaction” (McKenzie, 2013, p.378). If enacted, enablement can change the developmental trajectory of a person who may otherwise have been disabled by the imposed limitations of the social context.

The concepts of neurodiversity and disablement were discussed while referencing the reading excerpts. During the discussion I also introduced the idea of disability discourses, how they relate to the theoretical models, and attempted to elicit different voices through dialogue while participants related these ideas to their everyday practices.
CHAPTER 3

METHODS

Participants

Participants for this study were recruited from a non-profit voluntary organization in New York City that provides services to developmentally disabled people. This organization was selected due to my relation and familiarity with it. Any information that can identify the organization is maintained confidential in order to ensure anonymity. Participant recruitment began after approval was obtained from the City University of New York and the non-profit organization's internal review boards. To recruit participants, residential group homes and day programs in the participating organization were sent an invitation letter/advertisement flier to post for their employees. Fliers provided a brief description of the study, inclusion criteria, and my contact information. In total, two day service programs and ten residential group homes received the flier. The criteria for participation were the ability and willingness to provide informed consent, work directly with developmentally disabled people as a direct support professional, and willingness to relay thoughts and opinions during the two phases of data collection. Employees who were interested contacted me by telephone or email. Once an interested service provider made contact, I determined if the requirements for inclusion were met through a brief telephone conversation, email exchange, or in-person contact. A total of twelve people made contact but three were excluded. One person held an administrative/management position, another was a psychologist, and the third person was unable to commit to both phases of data collection.
Participants self-selected to participate in the study and nine direct support professionals completed the narrative phase of data collection. Of these nine participants, seven attended the focus group discussion. The two participants that did not attend the focus group relayed that personal circumstances arose and did not identify reasons related to the research for their absence from the focus group.

Prior to the narrative interview, demographic information was also collected through a questionnaire (See Appendix C). Table 2 consists of their responses to the questionnaire. The names listed are pseudonyms. Gender and racial identification were presented as open-ended questions so the term the participants used to described themselves are listed verbatim.

Table 2
Participant Demographics

<table>
<thead>
<tr>
<th>Participant</th>
<th>Work Setting</th>
<th>Years of work experience</th>
<th>Education</th>
<th>Gender</th>
<th>Race</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ann</td>
<td>Day Program</td>
<td>17</td>
<td>Associate's Degree</td>
<td>Female</td>
<td>Black</td>
</tr>
<tr>
<td>Alex</td>
<td>Residential</td>
<td>5</td>
<td>Associate's Degree</td>
<td>Male</td>
<td>Hispanic</td>
</tr>
<tr>
<td>Danielle</td>
<td>Residential</td>
<td>5</td>
<td>Some college</td>
<td>Female</td>
<td>African-American</td>
</tr>
<tr>
<td>Jessie</td>
<td>Residential</td>
<td>5</td>
<td>High school</td>
<td>Female</td>
<td>Black</td>
</tr>
<tr>
<td>Katy</td>
<td>Day Program</td>
<td>11</td>
<td>Some college</td>
<td>Female</td>
<td>Black/ Caribbean</td>
</tr>
<tr>
<td>Lawrence*</td>
<td>Residential</td>
<td>31</td>
<td>Some college</td>
<td>Male</td>
<td>Hispanic</td>
</tr>
<tr>
<td>Mary*</td>
<td>Residential</td>
<td>10</td>
<td>High school</td>
<td>Female</td>
<td>African-American</td>
</tr>
<tr>
<td>Susan</td>
<td>Residential</td>
<td>5</td>
<td>Some college</td>
<td>Female</td>
<td>Black/A-A</td>
</tr>
<tr>
<td>Veronica</td>
<td>Residential</td>
<td>2</td>
<td>Some college</td>
<td>Female</td>
<td>African American</td>
</tr>
</tbody>
</table>

* Did not attend the focus group discussion
Procedure

The study began with the collection of narratives from nine service providers, direct support professionals. After an interested employee contacted me, inclusion criteria were established and the narrative interview was scheduled. Interviews took place at times and locations that were convenient for participants. Interviews took place at participants' workplaces during their break, and prior or after their shift. Interviews were conducted in private offices with only the participant and myself present. All interviews were audio-recorded to ensure transcription accuracy. Prior to commencing the narrative interview, informed consent was obtained individually from each participant. I provided a brief description of the two phases of data collection and informed participants that I would not share any information provided during the individual interview at the focus group. Participants also completed the brief questionnaire on demographic information.

Narratives were used to provide information regarding participants’ understanding, ways of conceptualizing and speaking of disability. The narratives also served the purpose of providing insight to discourses and terminology used by participants. Narratives were elicited with open-ended questions. See appendix A for the questions that were presented to elicit narratives. Aside from the listed questions, I limited my responses to statements such as “tell me more” in order not to influence the participants’ accounts. The questions were intended to understand the discourses used by participants to define the people they work with, how they theorize disability, how they perceive their role in the work that they do, and their understanding of disability models and approaches. The narratives also served the purpose of providing insight to
participants’ discourses and terminology and explored their perceptions, from the perspective that they are experts on their own experiences.

At the end of each interview, participants were asked if they had any comments or statements aside from the questions I posed. I referred participants to web pages and excerpts from those sites to read at their leisure prior to the focus group. The web-based reading excerpts were intended to act as mediating tools to introduce interactional models on disablement and neurodiversity as they relate to disability discourses in situated practice.

Once narratives were collected, I facilitated a focus group discussion. The same participants that provided narratives participated in the focus group, except for the two people who completed the narrative but did not attend the focus group. The focus group discussion was scheduled on an evening that all participants agreed upon. The focus group took place nearly two months after the first narrative interview. The last interview took place one week prior to the focus group discussion. The focus group discussion was also audio recorded for transcription purposes.

During the focus group, I participated in the discussion and also served as moderator. The focus group discussion lasted one hour and forty-five minutes. In this study, I served the purpose of moderator in order to foster group interaction so that all voices and opinions were heard. I also presented the group with questions in order to provoke engagement and interaction (See Appendix B). The questions were posed one at a time and when the topic appeared to be exhausted, the next question was asked in order to keep the conversation flowing. I also
interacted and introduced topics in an attempt to collaborate on neurodiversity, disablement, and discourses as relevant to situated practice.

Although my areas of interest were primarily neurodiversity, disablement, and discourse and I attempted to introduce these topics, I followed participants' lead so the discussion was directed by participants. After participants discussed the questions, the reading excerpts were referenced. A majority of the discussion was started by the research questions I posed but discussions evolved into topics on situated practices. Discussion on the readings consisted of approximately thirty minutes of the focus group time and the readings served the purpose of provoking discussion topics. Participants were asked to discuss particular aspects of the readings that they found interesting or relevant to their work. Those areas of interest were then used to provoke discussion whether in agreement or disagreement. Participants were encouraged to relate the topics in the readings to their everyday practices.

Analysis

Narratives and focus group discussions were used to understand the theoretical standpoint of participants, in their voices, and provide insight into the enactment of these theories. Their understanding and ways of speaking of disability were used to understand their theories and discourses on disability. Their narratives discourses were also used for comparison to their ways of speaking during the focus group discussion.

I transcribed the narratives and focus group discussions line by line from the audio-recordings. The line by line transcription created the raw text. The narrative transcriptions yielded 754 lines and the focus group yielded 1097 lines of text. The transcribed raw text was
coded according to the steps of grounded theory (Auerbach & Silverstein, 2003). Raw text from the narrative interviews and focus group discussion were separately arranged into categories of repeating ideas and assigned a descriptive code. For instance, throughout both narratives and focus group discussions participants described the people they work with using words and definitions that were not disability-centered. All of these statements were arranged under the non-disabled definition. The codes, from my interpretation of the data, included: transformation of the individual, non-disabled definition, dependence and independence, role of direct support professional, everyday enactment, social construction of disability, role of family, deficit-based and medical discourses, socioculturally embedded discourses, lexicon of disability, and collaboration through dialogue. The coded text was combined to create code categories. The broad categories included: common traits, defiance of expectations, discourses, policy and regulation, everyday practice, dependence/independence, definition of individual, role of staff, and self-transformation. Each category consisted of a group of codes that were related thematically. The themes were then used to create a theoretical construct. From the data, four themes emerged: construction of the individual, relational construction of staff, contextualized interpretations of disablement, and enactment of deficit and social discourses through dialogue. The theoretical constructs were then used to create theoretical narratives elaborated in the discussion, “the narrative is the culminating step that provides the bridge between the researchers’ concerns and the participants’ subjective experience” (Auerbach & Silverstein, 2003, p. 40). The following section is a review of the study’s results. Raw text excerpts relevant to the themes are presented in an effort to represent participants' voices in their own words from their perspectives.
CHAPTER 4

RESULTS

The narratives and focus group discussion by service providers, told stories of the construction of developmentally disabled people that transformed from deficit-based understandings to relational representations of self and other. Participants explored the preconceived notions and stereotypes they used to understand disability when they first began working in this industry. However, through everyday interactions and situated practices they transformed their views of the people they work with and constructed their role based on their relationships. This relational construction of self and other, changed their views on disability as a deficit. Their stories demonstrated how service providers became agents for the people they work with, within the confines and parameters of regulations and institutional limitations. Throughout their stories participants discussed encounters with social and attitudinal barriers that they, along with the people they work with, tried to negotiate. Participants described how they observed the imposition of labels, stereotypes, and helped service users manage stigma. Participants also described the process of becoming staff through the everyday interactions with the people they work with, whom they referred to as the guys. They also described regulatory systems and institutional limitations, that they perceived as disconnected from the everyday practices of providing services, and as hindrances in their ability to exercise agency and advocate for the people they work with. Doing this work became a vehicle in the personal transformation of the direct support professional, an actor who provides services to the individuals, into staff an agent who knows the guys best.
Through participants' narratives and dialogues, disabled people were reconstructed from the imposed labels of *the individual*. *The individual* is a term from the local language that is service-driven. *The individuals* were reconstructed as *the guys* and *staff* emerged as a self-representation by service providers in situated practice. *Individual* is the word officially used, by the non-profit organization participants work for, to refer to developmentally disabled people who receive or use services. Through everyday enactments of the role of direct support professional, *staff* emerged as a self-representation that was relationally constructed to the people they work with, *the guys*.

*Staff* was defined relationally, occupying a space between the people they work with and administrators. *Staff* was in a position of power over the disabled person they work with but lacked power to effect change with administrators. Discursively this power differential is enacted through a redefinition of *individuals* and the creation of a familial category *the guys*. Administrators were assigned the category of the *higher-ups* that discursively and figuratively represented a position of power. *Higher-ups* were seen as disconnected from situated practices. Administrators represented policies and regulations that were perceived as restrictive and prohibitive both in the enactment of the role of *staff* but also in the autonomy of the people they work with, the service users.

Further, social barriers and regulatory mandates, such as levels of supervision, required *community inclusion* activities, and emphasis of health and safety determined in a top-down fashion were recognized as limitations in the everyday practice and in the social equity for disabled people. Participants described these mandates as restrictive even though participants recognized that health and safety was one of their primary responsibilities. Health and safety was
described as a justification for limitation of situated enactments of autonomy and independence as staff asserted the role of “knowing best.” Health and safety was a topic of discussion that demonstrated participants' recognition of the social nature of disablement but yet they both enacted and resisted dominant discourses on disability through a flux of deficit-based discourses and socially situated descriptions.

Participants’ perspectives were captured through both individual interviews and collaboration through dialogue during the focus group discussion. All data for the study came directly from these methods of data collection and participants' words are included verbatim in the results description. A review of the results demonstrated differences and similarities in participants’ narrative interviews when compared to their focus group dialogue.

**Narrative Interview and Focus Group Dialogue Comparison**

Narrative interviews were conducted prior to the focus group discussion to understand discourses used by participants, their perceptions of the disabled people they work with, and to understand how they view their role in situated practice. Narratives were compared to the focus group discussion to discern if there were differences in presentation of their views or their language used when speaking of disability individually and collaboratively with other participants. The following are some contrasts and comparisons noted among the seven focus group participants between their narratives and focus group dialogue.

**Katy.** During her narrative interview Katy enacted deficit-based language despite some portrayal of socially-contextualized disablement. In response to my first question “how would describe the people you work with?” Katy used the word *behaviors* to indicate whether a day is
good or bad. She stated, “some days some days it’s fine like there’s no behaviors no issues.” She also used the expression high-functioning to describe a person she works with in response to my question, “what is the person’s life like?”. Katy stated, “she has a good life. I heard now I know she’s still doing her work sites. She’s very uhm high, she’s very high-functioning.” From this description, high-functioning was associated with quality of life and participation in normalized activities, such as work. Work, however, was referred to as work sites. Work sites is part of the local language, a service industry dialect, that refers to a disabled person’s workplace. A non-disabled person goes to work whereas a disabled person goes to a work site. Katy also described her role in her work as someone who can provide friendship but in response to my question, “what are your thoughts on people’s abilities to make choices and decide for themselves?” she recounted how she designates one soda day per week for a service user. From her perspective, if she does not limit the frequency of soda consumption then the person she described would drink a soda every day compromising health and safety.

During the focus group discussion, Katy was reluctant to use deficit-based language. She whispered the word retarded and instead used the expression r-word. Katy also did not participate in the exchange between participants on functioning levels. She also spoke of a person she works with and her description defied stereotyped views of deficiency, “it doesn’t mean that they’re slower than others, they just, cause he knows how to count, he’s very smart.” Her interpretation of disability was socially situated and individually she spoke of disability through deficit-based terms. During the focus group, however, she looked at other participants to see if it was acceptable to use particular words within the context of their discussion.
Susan. Susan demonstrated similarities in her definitions of disability and her representation of her role across the narrative and focus group discussion. During the narrative she answered my question “how would you describe the people you work with?” with one initial word: challenging. Her narrative described disabled people as unpredictable and she stated, “I guess you’d say, mood swings one minute they are ok and you can talk to them and reason with them and the next minute they’re cursing at you, telling where to go, die, things of that nature.” She also used the words population and client in her descriptions of service users. These words were not used by other participants to describe the people they work with but they were mentioned by other participants as examples of older language used in this industry. Further, in response to my question, “what are your thoughts on people’s abilities to make choices and to decide for themselves?” she stated, “I believe everybody has the right to make a choice but by the same token if the person can’t quite understand certain things I don’t understand how they expect them to make a good choice.” Based upon what appears to be her view on disability as a personal deficiency, her representation of her role was that of someone who provides guidance because the people she works with cannot be expected to make good choices.

Similarly, during the focus group, when I asked “do you think the you work are different from other people?” she responded:

Susan: I mean they have their feelings, their feelings get hurt, they want love, they want attention just like we do. They feel sad depressed you know everyone feels like that at least once, so no not really, not very different but there is a difference.

Moderator: and what’s that?
Susan: Maybe they can’t control their feelings or emotions as well as a normal, I guess you say, person or a person that doesn’t have to take any type of medication to keep them calm.

Susan distinguished disabled and non-disabled people by the use of medications to control emotions and referred to non-disabled people as normal. Later in the focus group discussion, her interpretation of neurodiversity was development that occurs at a slower rate. Overall, Susan’s descriptions were based on a medical perspective in which disability was seen as deficit or disorder and as property of the person.

Ann. During Ann’s narrative interview and focus group discussion, she conveyed socially contextualized interpretations of disability and she demonstrated knowledge of the local language of service delivery. During her narrative, she described someone she works with as disabled by contextual factors, such as limitations imposed in group home settings. She used terms from the local language, such as travel-trained, the acronym MR instead of the words mental retardation, and she used expressions such as cognitive levels (instead of low or high-functioning) and the expression independent-living.

During the focus group, she maintained a socially situated interpretation of disability and equated social exclusion of disabled people to racism. She further explained, “it’s like they can’t drink the water. Everything, it’s separated. It’s segregation in a sense. It’s like they are not ready yet for that, did you teach them that, do they know how to sit, can they go into the restaurant. It’s just like that’s how I feel. It makes me want to advocate more for them.” Because of social exclusion, Ann identified her role as an advocate. She also discussed ways that she attempted to teach agency by encouraging the people she works with to speak up for themselves. Further,
during the focus group discussion, she used deficit-based words such as *retarded* but she said these words in a very exaggerated manner and over enunciated them. This act appeared to convey the pejorative and unsuitable nature of these words.

**Jessie.** Jessie’s interpretations and ways of speaking of disability attempted to assert the normalcy of the people she works with. During the narrative interview she responded to “how would you describe the people you work with?” by stating “they’re funny, have attitudes, they are everyday, normal people…they’re normal.” She acknowledged the limitations imposed by the service industry but she justified particular actions by claiming the primacy of health and safety. When asked to tell the story of someone she works with, she described a man who feels infantilized by procedures that require supervision. Jessie conveyed that she understood why he felt that way. However, later in the interview she positions herself and the organization as responsible for his health and safety so choices related to health needed to be limited.

During the focus group, Jessie identified the role of family as a disabling factor and described the people she works with as “adults with mental disabilities.” The age of the people she works with appeared to be relevant to Jessie’s definition of them and of their disability. She portrayed an understanding of the tension between agency enacted in adulthood and dependency of human services. She appeared to interpret the people she works with as wanting to assert autonomy and independence but limited by a regulated system. It should be noted that Jessie is a young woman in her early twenties.

**Alex.** Throughout both phases of data collection, Alex interpreted disability as an experience that is both internally and externally situated. During the narrative and focus group, he used deficit-based and local language such as *challenging* and *having behaviors*. He also
described the contextual factors that have disabling effects such as infantilizing by parents and limitations imposed by regulations.

Alex is the only participant who mentioned the service modality normalization. His discussion on normalization occurred both during the narrative and the focus group. During his narrative, he stated “we stress normalization but are we really treating them that normal? So I think that’s really my biggest thing that always bothered me. We stress normalization but then we don’t always do stuff that’s normal. So it bothered me. We stress normalization but then we don’t always do stuff that’s normal.” During the focus group he made an almost identical statement, “we stress normalization a lot but we really hinder a lot of the normal stuff.” According to Alex, his role and the role of the service industry is to provide a normal environment. During his discussion, normal was related to his own interpretation of what constitutes normalcy.

Danielle. Danielle’s interpretations and discourses situated disability internally as a personal deficiency but she also recognized the effects of socially disabling factors. During her narrative, she responded to my first question “how would you describe the people you work with?” by stating, “how would I describe them, well, I feel like most of them are independent for the most part and I feel like a lot of them are trying to show who they really are like they have a lot wants and needs but they kind of get depressed because they don’t have an outlet for it. I work with people who need help more than the average person.” She presented them as people who have more needs and require more help than non-disabled people but she attributed what she perceives are their feelings of depression to not having an outlet, not necessarily a personal deficiency.
Further, when asked “what are your thoughts on people’s abilities to make choices and decide for themselves?” she responded “with big decisions, we already know that they need help with that. If they can gain satisfaction with choosing what color shirt to wear today then I think that’s good but we know that they can’t say that they’re going to go get their driver’s license and drive around the block.” Choices were trivialized to minor decisions but the assumption was the disabled people are unable exert autonomy on decisions that are beyond mundane choices.

During the focus group discussion, Danielle discussed the role of contextual factors, such as discriminatory practices by non-disabled people. She also spoke of the effects that words and labels have on people. She proposed that no matter what word is used to describe disabled people, it will always have a negative connotation because of social attitudes. Danielle was the only participant to favor finding a cure for developmental disabilities, an argument that was in tension with other participants’ viewpoints. Danielle explained her stance on finding a cure as “not necessarily get a cure to change them and make them normal (yeah), that’s not what I mean.” She instead emphasized that research relevant to cure attainment would maintain disability as an active area of discussion and funding.

**Veronica.** Veronica’s narrative was based on a socially oriented view of disability. She primarily used words that described traits and characteristics that are non-disability centered. She used words such as friendly, outgoing, and intelligent when asked to describe the people she works with. Veronica also expressed the social attitudes that limit and exclude disabled people and consequently result in lowered expectations. Veronica also situated disability in social interactions with non-disabled people and with family members.
During the focus group discussion, she also maintained her assertion that disability is socially situated. Veronica directly opposed Danielle’s view of cure attainment research and she also expressed her disfavor of describing people as low or high-functioning. Despite her multiple descriptions of disability as socially situated there were also instances of deficit-based language. For instance, during a discussion on words used to describe disabled people’s actions, she stated “like a regular person goes to Starbucks every morning. That’s just their morning thing, that’s their routine. A regular person you’ll say that’s their routine, someone that’s developmentally disabled you’ll say they’re obsessed with coffee, why?” Her statement focused on the contextualized interpretation of disabled people’s actions but yet she used the expression regular person to refer to non-disabled people. From Veronica’s narrative and focus group descriptions, it seems that language is still in transition despite her social understanding of disability.

**Respondent Validation**

After analysis of narrative and focus group data, the participants discussed above were contacted in order to ascertain if the themes I interpreted from the data reflected their view. To ensure that data analysis and interpretation accurately represented participants' points of view, focus group participants were presented with a summary of the data, codes, and themes. Presenting data to participants is described by Bryman (2016) as “respondent validation, which is sometimes called member validation, is a process whereby a researcher provides the people on whom he or she has conducted research with an account of his or her findings. The aim of the exercise is to seek corroboration or otherwise of the account that the researcher has arrived at” (p. 385). For this study, summaries were emailed to participants and they provided feedback on
their own interpretations and their opinions on my interpretations of the data. The results from this study were supported by participants.

My interpretations of the data were corroborated by focus group participants who provided feedback after reviewing the focus group results. Of the seven focus group participants, six provided feedback to the results. Participants corroborated the change in relationship that occurs once individuals become the guys. One participant elaborated on the relationship that develops and reiterated that our guys are family and it no longer feels like work when that happens. Another participant emphasized that a major topic of discussion during the focus group, from her perspective, was the shared feeling of powerlessness “when we can't do things for them” because of limitations from management. She suggested having a focus group discussion with managers and administrators to understand their point of view. Another participant thought that labels was a prominent topic of conversation. She suggested that labeling people should stop but does not know how that would be possible. Her interpretation was that the term guys has emerged as a way of avoiding labels. However, without the diagnostic label “outside people” do not understand who is referred to when the word guys is used. Similarly, another participant indicated that he uses the word guys because he sees them as more than a diagnosis. From his perspective the most salient topics of discussion were the detachment from everyday practice by administrators, the affective bonds that are forged, and staff knowing the guys best because of these bonds. He explained that knowing best, from his perspective, relates to knowing their guys best not necessarily know what is best for them. He emphasized that people who are removed from everyday interactions “tend to forget that compassion and affection are human needs”. The
feedback provided by these participants appears to be congruent with the interpretations presented below.

**Theme Summaries**

Participants’ interviews and dialogues composed the raw data that were coded and then grouped into four conceptual themes. The themes were: construction of *the individual*, relational construction of *staff*, contextualized interpretations of disablement, and the enactment of deficit and social discourses through narrative and dialogue. The themes were evidenced in both narratives and focus group discussion but particular codes demonstrated differences in frequency and nature of statements. The following tables summarize the four themes and provide descriptions of each code with examples directly from the data.
Table 3
*Theme 1: Construction of the individual*

<table>
<thead>
<tr>
<th>Code</th>
<th>Code Category</th>
<th>Descriptive Codes</th>
<th>Examples from the data</th>
</tr>
</thead>
<tbody>
<tr>
<td>1A.</td>
<td>Exposure and</td>
<td>Statements on familiarity and changes in comfort level</td>
<td>Before...you was kind of like, what's wrong with her, stuff like that. So now that we work in the field, you embrace it.</td>
</tr>
<tr>
<td></td>
<td>transformation of the individual</td>
<td>Descriptions of disabled person as defying initial expectations</td>
<td>People don't realize that these guys are very smart, they underestimate them off the bat and that's not cool</td>
</tr>
<tr>
<td>1B.</td>
<td>Non-disability centered definition</td>
<td>Description of disabled person without making reference to disability</td>
<td>They are very outgoing, they remember a lot, they are very friendly. Everybody has their own personality.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Stories that do not mention disability or diagnosis as identity markers</td>
<td>They're funny, have attitudes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>They are every day normal people...they are normal</td>
</tr>
<tr>
<td>1C.</td>
<td>Negotiation of</td>
<td>Statements about service recipients’ independence and autonomy</td>
<td>We used to take the train to her job sites, she used to pick where she wants to work.</td>
</tr>
<tr>
<td></td>
<td>dependence and independence</td>
<td>Descriptions of dependence on direct support professionals for assistance and guidance</td>
<td>She still doesn't I guess quite grasp that, you know, she needs staff's help. She tries to do a lot of things herself versus asking staff.</td>
</tr>
</tbody>
</table>
Table 4

**Theme 2: Relational construction of staff**

<table>
<thead>
<tr>
<th>Code</th>
<th>Code Category</th>
<th>Descriptive Codes</th>
<th>Examples from the data</th>
</tr>
</thead>
<tbody>
<tr>
<td>2A.</td>
<td>Assigned role of direct support professional</td>
<td>Descriptions of perceived role as direct support professional</td>
<td><em>Community inclusion is good but it's not as person-centered</em></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Statements on policies and regulations pertaining to their role</td>
<td><em>We stress normalization but are we really treating them that normal?</em></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Statements on health and safety as job responsibility</td>
<td><em>We are in charge of other people's lives.</em></td>
</tr>
<tr>
<td>2B.</td>
<td>Everyday enactment of role of <em>staff</em></td>
<td>Statements on everyday practices</td>
<td><em>You have to have a lot of hats. You almost have to be like the big brother, you almost have to be a psychologist, you have to be a communicator, you have to know how to intervene.</em></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Role of direct support professional in everyday practice</td>
<td></td>
</tr>
<tr>
<td>2C.</td>
<td>Relational construction of self</td>
<td>Descriptions in personalized ways</td>
<td><em>It's like having a brother, sister, or family member.</em></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Statements that demonstrate common traits and parallels in experiences</td>
<td><em>It's the same way they're expected to learn from us, we learn from them</em></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Experiences of shared stigma, transformation of self</td>
<td><em>They don't like to pass this house...and one day it just really bothered me and I was like, 'we don't bite' and Raymond was like 'yeah we don't bite.'</em></td>
</tr>
</tbody>
</table>
Table 5
*Theme 3: Contextualized interpretations of disablement*

<table>
<thead>
<tr>
<th>Code</th>
<th>Code Category</th>
<th>Descriptive Codes</th>
<th>Examples from the data</th>
</tr>
</thead>
<tbody>
<tr>
<td>3A.</td>
<td>Social construction of disability</td>
<td>Statements on social and attitudinal barriers</td>
<td>It's like racism.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Descriptions of disability as a socially constructed category</td>
<td>It's a label.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>It's all about your place in society.</td>
</tr>
<tr>
<td>3B.</td>
<td>Role of family in disablement</td>
<td>Accounts on infantilizing by family members</td>
<td>I have one guy. Rick, his family treats him like a baby so you know he never really gets the chance to learn.</td>
</tr>
<tr>
<td></td>
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<td>Statements on rejection by family</td>
<td>I think their family thinks because quote unquote something is wrong with them that they can't bring around, they don't want to be around as much, and they don't realize that that is so hurtful.</td>
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<td></td>
<td></td>
<td>Statements on the effects of perceived parental guilt</td>
<td>They feel bad. They feel like it's their fault for having a kid like this.</td>
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<tr>
<td>3C.</td>
<td>Policy/Practice disconnect as a disabling consequence</td>
<td>Descriptions on the effects of policies and regulations on the limitations of everyday choices, statements on the impracticality and restrictions imposed by certain policies</td>
<td>Weekends it's usually where we try to take them out and stuff like that but even that's hard since he's 2:1 in the community. So usually to get to, there's extra staff cause we have what three 1:1's in the residence.</td>
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</tbody>
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### Table 6
**Theme 4: Enactment of deficit and social discourses**

<table>
<thead>
<tr>
<th>Code</th>
<th>Code Category</th>
<th>Descriptive Codes</th>
<th>Examples from the data</th>
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<tr>
<td>4A</td>
<td>Deficit-based and medical discourses</td>
<td>Situating disability within the person</td>
<td><em>They don't think clearly all the time.</em></td>
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<td></td>
<td></td>
<td>Statements on functioning levels</td>
<td><em>Maybe they can’t control their feelings or emotions as well as a normal, I guess you say, person</em></td>
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<td></td>
<td><em>She's very high-functioning. I know she, I think she works at an office.</em></td>
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<td>4B</td>
<td>Socio-culturally embedded discourses</td>
<td>Statements on disability as a difference</td>
<td><em>It doesn't mean they're slower than others...he's very smart.</em></td>
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<td></td>
<td></td>
<td>Statements on acceptance and references to aspects of neurodiversity</td>
<td><em>Autism acceptance means you're accepting the person because they're different.</em></td>
</tr>
<tr>
<td>4C</td>
<td>Lexicon of disability</td>
<td>Discussion on words and use of the local practice-based language</td>
<td><em>The individuals, my guys, population, retarded, high-functioning, consumer, support/control</em></td>
</tr>
<tr>
<td>4D</td>
<td>Collaboration through dialogue</td>
<td>Moments of agreement or disagreement on terminology during discussion</td>
<td><em>D: I honestly don’t see nothing wrong with the term mental retardation. I think that it’s been used out of context so much that people make it seem like it’s a bad thing. Kids will call it like ‘oh you’re retarded’ and it’s like ‘no you’re retarded’. But then like what is retarded?</em></td>
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<td><em>A: people just use the word not really knowing what it is</em></td>
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<td></td>
<td></td>
<td><em>D: I don’t think it’s a bad thing. It’s only a bad thing when you agree that it’s a bad thing.</em></td>
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Theme 1: Construction of the Individual

The first theme, construction of the individual included narratives and discussion that described the individuals reconstructed as the guys. The term guys was used in a gender neutral way in this context as it referred to both men and women. This theme encompassed discussion on the ways that participants changed their views regarding the people they work with after developing familiar relationships. This theme includes ways of defining disabled people that are not disability-centered and do not mention diagnoses. It also includes participants' attempts to negotiate disabled people as independent despite the perception of dependency that receiving services and support from staff creates.

Code 1A: Exposure to and transformation of the individual. Code A in the first theme included statements on familiarity, changes in comfort levels, and descriptions of disabled people as defying initial expectations. Participants described feelings of trepidation when they initially began working with developmentally disabled people. Their expectations were based on cultural narratives that describe disabled people as outsiders. Through interaction and engagement participants describe the people they work with as defying these initial preconceptions and in turn participants experienced a change in their level of comfort with the people they work with.

Narratives. During narrative interviews, statements relevant to this code category were expressed by two participants, Katy and Lawrence. In response to my question: “what are your thoughts about people’s ability to make choices and decide for themselves?” Katy stated “you’ll be surprised and they know and they’ll remember. People don’t realize that these guys are very smart, they underestimate them off the bat and that’s not cool”. Katy mentioned how non-
disabled people conceptualize developmentally disabled people as lacking intelligence. Katy also expressed her disapproval of lowered expectations and the presumption of incapability. Katy used the term guys to refer to the people she works with. Her expression 'you'll be surprised' implied her own initial disbelief that was disproved once she realized their capabilities.

During his individual interview, Lawrence recounted his experience of getting to know the people he works with. In response to the question “how would you describe the people you work with?” he described his experiences as a relationship-building process. There were difficulties in the beginning but then a level of comfort was achieved through a mutual process of establishing trust. He stated, “I think that’s very important on how you relate to them so with the guys that I got it’s like at first it’s like anybody else you learn them and in the beginning and sometimes it gets rough but after a while you get a comfort zone and they know you and you know them and then a lot of things can go on from there”. Comfort was achieved once he was able to know them as people with distinct traits and Lawrence too used the term guys to describe the people he works with.

**Focus Group.** During the focus group, statements coded under exposure and transformation of the individual were made by four participants during an exchange on their evolving views. From their discussion it seemed that participants initially expected someone who lacked capability but this perception shifted and was transformed through direct interaction. Participants described people who were capable of doing things they did not initially expect them capable of. They were transformed from people with disabilities into people with personality traits and abilities. Participants relied on deficit-based stereotypes and cultural narratives before their views were transformed through everyday interactions and this can be summarized by a
statement Susan made: “when you’re not around them, you don’t understand.” During an exchange, participants shared common experiences in their initial reactions to developmentally disabled people. They came into this field of work with knowledge of deficit-based, stereotyped views but participants expressed changes in their conceptualizations of the people they work as a result of their direct engagement:

Alex: before when you was younger you was kind of like…. (background: is she slow?) what’s wrong with her stuff like that so now that we work in the field, you more embrace it we like to see stuff like that (background: we understand it a lot more)

Katy: cause I was like that too. Like when I first started working here, I thought maybe a year or less. Cause I could not be around this, I’m not gonna lie, them people for too long. It’s a lot. I was scared. I was scared. I remember my first day here. It was a big blow out with me and I’m in the corner crying. (laughter) I called my grandmother and said I don’t know what I did to these people I don’t know what to do. She was like you know what, come home, come home now. (laughter) to walk off cause I couldn’t take it. I was scared of them. I understand how some people can be cause I didn’t know. It was first time in the field, never worked this population at all, I was scared. But it’s about 12 years later I’m still there. What? I wish. I know I know them like nothing I’ve seen it been it done it all already. But in the beginning I gave myself, no lie, a year before I was going to leave. Second day here I was going to walk out. I worked in this house. I was like can’t stay here. I’m like I’m scared. I can’t stay here. So I understand how some people are like that, cause they don’t know.

Susan: When you’re not around them you don’t understand.
Katy: Exactly, exactly what that noise is or now they’re doing that they’re gonna jump at me

Susan: and then you always hear that they’re really strong

Veronica: Exactly

Susan: that they’re on meds so they’re gonna do this or do that

Alex: they’re all really strong

(background: laughter)

Susan: yeah but you get a little more nervous when you don’t know them

Participants’ discussion demonstrated several of the preconceptions that they brought to their work before directly interacting with developmentally disabled people. Alex described how he once thought developmentally disabled people had something wrong. In response to his statement, an unidentifiable participant voice in the background posed the question, is she slow? These statements demonstrate the assumption that developmental disability implies delayed or hindered growth. The story Katy shared in response to Alex's remark exemplified the experience shared by several participants when they first began working in this field. Katy felt frightened because she did not know them and came to this field of work with preconceived notions and stereotypes that defined disabled people as outsiders who are unknown and potentially dangerous. Katy described how she now understands why people who are unfamiliar with disabled people may be apprehensive because they do not know them and rely on these stereotyped views as the representations of disability. During her narrative interview, Katy expressed that people underestimate service recipients and during her focus group discussion, she included herself as someone who had preconceived ideas when she first started working.
Susan and Alex jokingly described some of the initial stereotypes, such as they are on medication and therefore unpredictable or that they are unusually strong. Susan, however, makes a distinction during other exchanges in the focus group discussion between disabled people and non-disabled people by asserting that disabled people take medications to control their emotions. She stated, “maybe they can’t control their feelings or emotions as well as a normal, I guess you say, person or a person that doesn’t have to take any type of medication to keep them calm.” It is unclear from the interaction above between Susan and Alex if she indeed was initially joking about disabled people taking medication or if she presented this statement jokingly due to the responses from other participants.

The feeling of initial apprehension due to preconceived ideas and lack of familiarity was shared by several participants. These statements elicited laughter from other participants in the focus group, an indication that there was consensus that these are known characterizations that they can now dismiss because they understand the erroneous nature of these stereotyped views. Participants expressed that through direct interaction and engagement, they changed their views of developmentally disabled people from cultural stereotypes to individualized understandings.

Transformation of initial expectations that the people they work with were incapable, unpredictable, and even scary occupied several exchanges during the focus group. Participants expressed that through interactions and shared space, they began to see the people they worked with as individual people. For instance, Alex said:

I would say now before you really…I wouldn’t say you didn’t like them but kind of, like, wanted to stay away from them because you like really didn’t understand them but now
it’s like sometimes I like a certain one for personal reasons (yeah, yeah) before it was because they just were a little different now it’s because this guy’s gonna do, he purposely doing something...Cause I, I’m not going to sit there and say that before I started working I wasn’t a little curious a little you know move away from them a little bit but now that I started working with them now I see like, for example, a little girl with autism and I think it’s the cutest thing in the world.

Alex expressed initially feeling apprehensive interacting with them, as well as, feelings of curiosity due to lack of familiarity; however, these feelings later changed when he made sense of their behavior as an act of volition that was more a personal disposition rather than pathology. Difference was no longer scary since it was no longer unknown. He talked about how he now sees an autistic girl and thinks that she is cute, demonstrating that autism is no longer primary identity marker. From his description, autism became part of the child's cuteness and defied the cultural narratives on autistic children as tragic and pathological. From participants' statements, it can be deduced that exposure and familiarity led them to see the people they work with beyond diagnoses or labels. Behaviors were not pathologies or seen through a lens of a diagnosis. They began to relate and build relationships based upon personality compatibility and common interests.

Alex further related this same experience of development of familiarity and transformation, by non-disabled people, or community members as described by participants. Community members refers to non-disabled people who do not work in human services and are not relatives of the people they work with. Community members is a term that is part of the local dialect or local language of the organization they work for. Alex relayed a story on the
transformation of perception and attitudes of business owners as they became familiar with and began to know developmentally disabled people:

Sometimes they [the community members] actually want to interact also. You will see somebody go to the store all the time. Before the guy used to just stare at him but now they come in and the guy knows their name. They come in and they start saying hey what’s up, how you doing buddy. Now you know the society everyone in the community starts you know kind of realizing who they are and say hey to them. So I guess once they see OK these guys are not that bad now let me talk to them. So everyone starts getting comfortable and you know soon they look at them as another person in a way.

The process he described goes from unfamiliarity and discomfort and progresses to getting to know the person. He equated it to getting to know any person and disability was no longer seen as an identifier.

Veronica also described how people who are unfamiliar with her work first respond and how an insider perspective can lead to a different view of developmentally disabled people. She stated, “when you describe your job, they think it’s like oh my God, and right off the bat I would tell them it’s definitely not what you think. What you see from the outside, it’s a completely different story once you get on the inside. They’re very nice, they’re very friendly.” The dichotomy of outside/inside is reversed in which the outsiders are the community members who lack exposure and direct knowledge of disabled people and rely on stereotyped views. Whereas, someone on the inside has knowledge of disabled people, who are seen as people with both favorable and unfavorable traits regardless of disability.
**Code B: Non-disabled definition.** Code B in theme 1 included descriptions that did not refer to or mention disability or diagnosis as identifiers. Exposure and familiarity allowed participants to become comfortable with the people they work with and this experience was heard in their descriptions. Descriptions under this code referenced personality traits and individual characteristics without the mention of disability, diagnoses, or other label in the definition of disabled people. These descriptions were in response to the question I posed during the narrative interview: “how would you describe the people you work with?” This code was only observed during the narrative interviews. Similar accounts were noted during the focus group but those discussions focused on finding common traits between participants and the people they work with, so they were coded under theme 2 code C.

During narrative interviews in response to the first question I posed, “how would you describe the people you work with”, five participants responded with descriptions that were not deficit-based or disability-centered. Ann, for instance, focused on the personalities and ordinariness of the people she works with.

Researcher: How would you describe the people you work with?

Ann: The individuals…uhm a lot of different personalities I would say interesting.

Researcher: Tell me more

Ann: Oh gosh to me it’s like a little high school Smithtown High (laughs) because you know they want to belong, they’re trying to identify and fit in, and it’s a lot you know uhm they always concerned about their how they look how they talk, they want approval, they want acceptance. And it’s so nice to me because they know I have an open door they’re just like how do you think I did this? And you know it’s just every day is different
there’s no same day same thing it’s just a group of interesting people who wants to be as normal as they can be, you know.

In this narrative, Ann described the people she works with in relation to normative behaviors. They presented traits typical of all people, such as seeking acceptance, self-identification, and experiences of interpersonal conflicts. In her description she notes the social barriers that impedes their desire to fit in but yet uses deficit-based language in her description. She referenced how they seek her out for guidance and support and she ended her description of their desire to be 'as normal as they can be'. Ann uses the word normal to assert their ordinariness and sameness, not as a comparison to a normative standard. The description of disabled people as ordinary is further exemplified in Jessie's narrative. She responded to this question with an assertion of their normalcy, “How would you describe the people you work with? They’re funny, have attitudes, they are every day, normal people…they’re normal”. She repeated normal to emphasize that the assumption may be that they are different and not normal. These two participants recognized the search for normalcy and qualified the people they work with as being normal.

Two other participants, Veronica and Mary, also avoided disability-centered descriptions. Veronica described individual personality traits and Mary qualified the people she works with as family members.

Researcher: How would you describe the people you work with?
Veronica: The residents? They are very outgoing. They remember a lot. They are very friendly. Everybody has their own personality...They’re very nice, they’re very friendly.
Veronica presented traits that defied the stereotyped ideas of developmentally disabled people. She specified that they are outgoing, remember, and are friendly. She also does not define them as one generalized group and specified that they each have their own personality. Her answer to my question does not include deficit-based language or descriptors that reference disability.

In Mary's account, she personalized her relationship with the people she works with and described them as family members. From Mary's narrative: “How would you describe the people you work with? The staff or the individuals? The individuals? Well I’ve been working with them for a long time so I think of them as part of my family, which they are… family. I think of them as part of my family”. Mary initially used local language *individuals* for clarification from me as to who I was referring to. Her view was personalized as she progressed from thinking of them as family to reaffirming that they are in fact part of her family.

Unlike participants who relied on non-disability centered descriptions, Danielle's response to this same question contained elements of both personal deficiencies and environmental limitations.

Researcher: How would you describe the people you work with?

Danielle: How would I describe them, well, I feel like most of them are independent for the most part and I feel like a lot of them are trying to show who they really are like they have a lot wants and needs but they kind of get depressed because they don’t have an outlet for it. I work with people who need help more than the average person.

Danielle’s response described the people she works with as independent but she also constructs them as people who have a lot of wants, more than the average person.
Negotiating independence while relying on service providers became a topic mentioned by several participants, unexpectedly. Participants attempted to make sense of independence as something that is mandated by policy, such as principles of person-centered planning, but yet sometimes impractical in the everyday practice. Independence and autonomy were seen as concrete but yet ephemeral qualities that are given by service providers but can also be taken away. Despite independence mandated as a right, it is at times withheld. Lack of independence was perceived by participants as a source of frustration and apathy for both service providers and disabled people. Participants did not identify independence from human services as a possibility.

**Code C: Negotiation of dependence and independence.** Code C in the construction of the individual theme, included statements that related to the negotiation of independence and dependence. The individual was constructed as a person who is dependent upon others, service providers in particular, to give them independence. Independence was spoken about as a concrete quality that service providers are both mandated by policy to give and is either withheld or granted in practice. Disabled people relied on service providers to give them opportunities in which they can exercise independence and also relied on staff to teach them the skills perceived as necessary to be independent. Independence and dependence were discussed during narrative interviews and during the focus group discussion.

**Narratives.** From the individual narratives, independence and dependence was mentioned by seven participants. Danielle, for instance, described a woman she works with, Carol, as needing more help than “the average person.” Carol has an adult child and it was a source of dissonance for Danielle when she tried to make sense of a person who relies on services but is a
parent. Danielle talked about how surprising it was for her to find out that Carol has a child but yet lives in a residential setting.

Danielle: I work with people who need help more than the average person...I think Nancy Stevens because she has a child so people wouldn’t really, I mean it caught me off guard when I found out. Not that’s impossible but you’re living in a group home but you have a child.

In her statement “you're living in a group home but you have a child” showed the contrast between an act that is perceived as requiring independence, having a child, but is incongruous to the perceived dependence of people who live in group homes.

Carol's age is also relevant to Danielle's negotiation of independence and dependence. Danielle is a woman in her late 20's and Carol is over 60 years old. Carol relies on Danielle for assistance and Carol perceives Danielle as a caretaker. This was noted in Danielle's narrative, “sometimes I feel a little funny because she’ll say you’re like a mom to me and she’s old enough to be my mother, my grandmother even. So I’ll kind of let her know that but I still understand why she says it. I’ll tell her you’re like a big sister to me and I just try to I just try to give her like positive reinforcement when she does things.” Danielle's account demonstrated that she praises Carol when she demonstrates autonomy and uses the expression positive reinforcement. Positive reinforcement is a clinical term used in the local language of service delivery to signify praise for actions that merit approval from the viewpoint of the service provider. During this narrative Danielle also demonstrated role confusion due to age difference and the positions of service provider and recipient.
In other narratives, participants negotiated disabled people's attempts at exerting independence. Independence was set as an attainable goal that a person can achieve if they gained skills to approximate normative functioning. In the following account Susan also referred to Carol, the woman with a child described by Danielle:

Susan: She was independent at one point so now she basically depends on staff to help her out with different things… She said she lived on her own and she was able to go to her appointments by herself she was going out to the community by herself handling her own personal business you know like hygiene and everyday errands for her everyday households for herself.

Susan defined independence as Carol's ability to take care of everyday responsibilities and this was not currently her circumstance as she depended on others for things she was once able to do on her own. Reliance on service providers signified to Susan that Carol had lost her independence.

Independence was also spoken about as something that the disabled person achieved. The achievement of independence was measured by the approximation to normalized behaviors. In her narrative, Ann spoke about Clark in response to my request to tell the story of someone she works with. Ann described how Clark was able to achieve some normalized behaviors that were indicative, in her view, of his ability to gain independence. She recounted how he is now able to travel on his own since he is travel-trained. Travel-trained is local language for someone who has been taught how to use public transportation or navigate their neighborhood without supervision from service providers. She used the expression “he has come a long way” to show
that he went from a circumstance in which he was dependent on others, such as his family, to a point where he is able to do things for himself.

Researcher: Tell me about a person whose story you would like to share?

Ann: Oh, let’s see. There’s one person, Clark, uhm him and me have a very good bond. He’s come such a long way with his independence trying to be traveled trained and do lots of stuff on his own and with…had a lot of setbacks as far as transitioning from living at home and that’s all he knew to ah his mother and his parents getting ill and him having to come out the home and live in a residence and ah there were a lot of difficult days for him… in the beginning it was real rough but they were uncertain about their weight and uhm everybody you know you gotta lose weight and he was self-conscious and he had a girlfriend. And uhm scared to leave home and his life was just everybody telling him what to do. He didn’t really have no safe zone in his life. And uhm him thinking about and him sharing with me that he felt like he just wanted to run away which was kind of scared me but he confided in me saying that they’re always telling me what to do and I’m not a baby. I said you gotta speak up for yourself when they tell you you gonna eat this you say you know do I have a choice?…So his life he had to advocate for himself and he never had to do that because he lived at home all his life and he also had his mother and people to look out for him but now that he was on his own he had to go learn laundry, cooking skills, everything so gaining independence it’s not just the whole point of now you’re an adult now you’re 21, it was him just accepting who he was and trying to make positive changes for himself not just for today but for his future he set out a map he said uh in one year I’m going to do this and he met all those goals it’s started off on a decline
but it escalated in to something beautiful cause he the person he is now is he has confidence and he never had that before so it was a lot of consistency working with him reassuring him and to showing him different things and help him from going from having no phone to a regular phone to a Verizon account and learning how to save money oh I can go to the corner store by myself now I know how to catch the bus.

In her account, she talked about all the areas in Clark's life in which his independence was taken away. These areas were as mundane as food choices and as life changing as having a girlfriend. Due to lack of independence, there was a reliance on others for assistance so he experienced fear and apprehension in making his own choices. Ann also mentioned the effects of surveillance and monitoring on Clark’s self-image and how he felt self-conscious about his weight and appearance.

Another narrative, took the perspective of the disabled person and how this particular person perceived and experienced the lack of independence.

Jessie: Well if you, I think he has a pretty decent life but what he says, he says that he feels like he’s confined, because you know we just took over, but he just says that he feels like he wants to go out and do things on his own and he feels like we are babying him, so to speak.

Jessie described how Organization A took over this person's residence. As a result, there was a shift in policies and procedures that had direct effects on the everyday lives of people who receive services. Jessie alluded to an increased level of supervision that removed this person’s choice to go outside alone. *Staff* supervision was perceived as infantilizing and Jessie described his feelings of confinement by greater surveillance. In this narrative the limitation of
independence was an element of maintaining health and safety protocols. This person was unable to travel alone until it was administratively determined that he had the capability and skills to do so.

Other participants, Veronica and Mary, saw it as part of service providers' role to promote independence despite dependence on services. Independence was described as a set of traits that service providers can teach and give to the people they work with so that they are able “to do more” for themselves. But as independence increases then the need for the service provider's assistance decreases. In order to negotiate the decreased need for assistance through independence, individuals are constructed as people that can be independent only with the assistance of service providers, therefore, making them dependent indefinitely.

Veronica: I like being here so that I can make a difference in their lives. Help them to do more than people expect them to do, you know. They are very capable of doing a lot of things but if everybody always does it for them when will they learn to do it for themselves. So I try to help them be more independent.

Mary: I help Alice express herself more, you know, often and getting her to try to do more and be more independent. Go to the store, you know, around the corner and just be more independent…I’m getting stuck…just help her to do more, to be more herself as possible as she can.

Veronica and Mary both mentioned independence as a goal in service provision but not necessarily independence from service provision. Other participants focused on dependence on service providers. When disabled people attempted to do things without assistance it was described as outside of the role of the individual positioned as reliant on service providers. This
was evident in Susan's account of Carol. It should be noted that Carol is the woman mentioned earlier that has a child. Susan stated, “she still doesn’t I guess quite grasp that you know she needs staff’s help she tries to do a lot of things herself versus asking staff or if she needs staff’s help she doesn’t go to staff and speak to staff she waits until they come around.” Susan described Carol's attempt to exert independence by doing things on her own but yet saw her as passive by waiting for staff to come around instead of speaking up and asking for help. Carol was presented through a duality of independence, presented as an act of volition that can be detrimental, and resistance to dependence, by not asking for help from staff members. When I asked Susan how she saw her role in her work, Susan responded: “guidance, I guess you can say. Uhm to help her listen to, for example, for the appointments she’ll ramble on and she won’t listen to what the doctor is saying so I say it’s to interject and to explain to her and be the mediator between her and the doctors.” In this instance Susan positioned herself between the us/them, insider/outsider binaries. She described Carol as someone who rambles when she speaks to doctors. The doctor was positioned as an expert and the role of the service provider, in Susan's description, was to act as an intermediary between the expert and the disabled person whose voice and opinions were reduced to rambles. Susan went further to say, “I think they need help. I think they need staff representative to make that choice for them because they don’t think clearly all the time.” In this narrative, the individual was constructed as someone who is dependent on service providers due to personal deficiency.

Lawrence's narratives also demonstrated dependence on service providers; however, in his account he talked about subtle ways in which service providers gave the perception of
independence but the disabled person still relied on staff to make decisions and choices on everyday tasks.

Lawrence: sometimes they can have, sometimes they can do good but a lot of times they need the support of the workers to kind of rationalize the best choice. They may make a choice but it may not be the best thing exactly. Paul sometimes may want to do his lunch, he may want to go to the bathroom, and he may want to do his clothes. And he knows that he wants to do a choice but he’s not quite sure which of one he should to do first. So a lot times you have some people you have to guide them into like maybe what do you think, like not making the decision for them but maybe guiding them in what they should do.

From Lawrence's account there was a presumed need for service providers to intervene in the guise of a choice.

**Focus group.** Service approaches, such as person-centered planning, mandate opportunities for the exercise of independence but yet these same policies were viewed by participants as restrictive in the ability to provide independence to the people they work with. During the focus group discussion, participants reflected on what life in a residential setting must feel like relevant to independence:

Alex: I’m not only going to talk about the negative. These guys do live better lives also in a way… I mean

Moderator: than what?

Alex: you get three hots and a cot (laughter)
Moderator: what does that remind you of?

Ann: jail

Susan: an institution

Ann: yeah but I mean

Susan: there are rules and regulations. You gotta do this, you gotta do that

Alex: yeah you get three guaranteed meals. I’ll be lucky enough to get two sometimes.

Susan: but you can do whatever you want, whenever you want, and however you want.

If you want to go to the strip club you don’t have to ask management to go the strip club.

You go check your bank account and see if it says it’s OK. That’s how it is. These guys have to ask management, it depends what management feels it’s OK. That’s not right.

Veronica: Sometimes I agree with him. You know they’re living in a nice house. They get to take showers for as long as they want. Shoot if I was in a house the time in the shower would be limited cause I don’t want to pay that water bill.

Susan: but then you have to do what people tell you when to do and how to do it.

Danielle: how many potatoes can you eat

(inaudible)

Ann: I’m going to take out these 5 sodas for the week

Susan: and if you drink all 5 of them in one day for the rest of the week you don’t have any

Alex: there are pros and cons to it. A grown ass man has to have like this little bit of rice.

I hate seeing that. You trying to feed him like a 13-year-old girl. That’s a grown man.

Why are you not feeding him like a grown man? I understand they have diet things but…
During this exchange, Alex attempted to point out the positive aspects of living in a residential group home. Participants demonstrated knowledge of historical practices of deprivation in institutionalized settings and instances in time when basic needs such as three meals and a bed were not part of everyday practice. Ann, however, equated basic needs being met as something that also occurs in jail and as Susan relabeled, another type of institution. In their discussion, basic needs were overshadowed by lack of independence, such as having to ask management to do things they want to do. Susan mentioned that Alex's ability to engage in an activity, such as going to a strip club, is mitigated by economic resources whereas the people they work with have to ask if they can do so.

Their discussion then evolved into the control and restriction of food which earlier in their exchange was seen as something taken for granted. Alex talked about “diet things” [nutritional plans] to justify the limitations and restrictions but yet he saw it as unfair to control food. Although he explained he understood the purpose of nutritional plans, he saw it as a rule or mandate that interfered with the exercise of independence and autonomy in something as basic as food choice. Nutritional plans also transferred control of a basic need to service providers who either granted or restricted food based upon written plans or personal discretion. Food intake became one of many aspects in the individuals' lives that were monitored, under surveillance, and restrictions were justified as a protection of health and safety.

In the construction of the individual theme, participants provided accounts on the cultural and societal perceptions of the people they work with as their initial starting point. These preconceptions were transformed through everyday interactions through a process that led to knowing, becoming comfortable with, and then relabeling the individual, the guys—a term used
by all participants. Through this process, participants described and defined the people they work with by noting personality traits without reference to disability or diagnoses. In their construction of the individual, participants attempted to negotiate the regulatory mandates of providing independence but independence became a concrete action that was taught through normalized behaviors. Although participants constructed the people they work as capable, reliance on services perpetuated dependency on service providers. Service providers in turn constructed their own role, as staff, in relation to the guys they work with.

**Theme 2: Relational Construction of Staff**

Another theme noted in the data was participants’ representation of their role in the work that they do. The definition of their role was relevant to their relationships with the people they work with and they created a role referred to as staff. Participants' job title is direct support professional but yet participants did not refer to themselves as such. Instead, they used staff, a position that was relational to the guys and held power in their perception of knowing best. Staff in relation to managers or administrators became a devalued position that was perceived as powerless in the ability to effect change and act as an agent on behalf of the guys and on behalf of themselves. Therefore, the role of staff was relational to both disabled people and to administrators. A parallel existed in the experience of power differentials that resulted in participants’ perceptions that they too were part of a disempowered group. Participants spoke of identification with the people they work with and a representation of self that was relational. Participants stated that they learned and developed from their interactions with disabled people and described themselves in terms of those relationships.
Code A: Assigned role of direct support professional

The first code in this theme, was participants' perception of the prescribed role of the direct support professional which was a role that differed from what they perceived everyday practice. This code included statements that provided descriptions of the perceived role as direct support professional, statements on policies and regulations pertaining to that role, and statements on maintaining health and safety as the primary job responsibility. The prescribed role made the direct support professional an actor that enforces plans and policies. This prescribed role, however, was perceived as interfering with staff’s ability to act as an agent and provide independence, autonomy, and choices.

Narratives. During narrative interviews, in response to my question “what do you see as your role when you work with this person” after they told the story of someone they with, participants explored what they perceived as the role of the direct support professional and what they perceive as their role as staff. Part the assigned role of the direct support professional is to safeguard the people they work with. In his narrative, Alex talked about the difficulties in maintaining a safe environment and referenced particular policies that interfered with his ability to carry out what he perceived as his actual role:

Alex: Try to keep him and everybody else safe. That’s always like a big thing with him cause he has a habit of just springing up and sometimes he may go after an individual and the problem with that is you know you have to now be accountable for two different individuals. And since it’s 1 to 1 you always gotta make sure he’s a person where he’ll be sitting right here and just get up and run out of nowhere. And you have to be on your P's
and Q's cause as soon as he gets up and runs, you got to go right with him. To keep the 1 to 1 protocol and keep him from throwing himself and he does have pica so now you got to worry about him putting something in his mouth. It’s like so much goes on with him cause you have to do pica sweeps, make sure nothing is on the ground, but then again you never really get a chance to relax, pretty much, not really relax but you don’t get a chance to calm down cause if you are having a bad day and you’re coming into work your day is only going to get worse.

The responsibility of ensuring health and safety is compromised by what Alex described as the person’s behavioral displays and diagnosis. Alex was mandated to provide one to-one supervision for this person and he described the individual as “a one-to-one.” He described “one-to-one’s” as posing more of a challenge in following the direct support professional role. He also mentioned that the person has pica so Alex must be more vigilant as this person may eat an inedible object which would compromise his health and safety. The person's level of supervision and diagnosis were identified as sources of challenges.

During his narrative Alex mentioned normalization as one of the standards that drive services. Normalization, however, is not overtly mentioned in current policies but yet he perceived it as the standard of service delivery. Alex stated, “we stressed independence…or normalization. That’s the word…a term that always bothered me. We stress normalization but are we really treating them that normal? So I think that’s really my biggest thing that always bothered me. We stress normalization but then we don’t always do stuff that’s normal.” In addition to safeguarding the individual, Alex saw as part of his mandate to provide opportunities for normative behaviors and experiences.
Alex went on to describe how direct support professionals are taught to separate their personal life from their work and maintain a depersonalized role. During training the direct support professional was taught not to let personal factors influence the work that they do, as Alex stated, “and you know they teach you to keep your outside stuff outside and then with him if you bring the outside stuff inside then you can really have a horrible day. So I guess it pretty much trains like you know you come to work to work, don’t let the outside stuff influence your work inside cause if you do let it can leak inside, it can be really bad.” The everyday practice of service delivery, however, was a very personal experience as described by participants. Participants work inside the homes of disabled people so it was both a natural home setting but it was also an artificially constructed environment of service delivery.

Two other participants described what they perceived as their role in maintaining health and safety as it related to medical care. In their narratives, medical care should not be a choice because it impedes staff’s ability to safeguard the individual.

Susan: So I think certain things should be looked over. I think this population should be protected a little bit more under when it comes down to very important things like their health you know basically but as far as what program they want to go to or have their room hooked up if they want it pink or purple or dirty clean I think that’s totally their choice.

Jessie: Because he wants to go out and walk around by himself and he’s complaining all the time about it but I’m like you can do that, but we you know, this isn’t a problem with you wanting to walk around and stuff like that but we have to know where you are you just can’t go walking around by yourself. We don’t want nothing
to happen to you but he just don’t get that… I think like he like to consent for himself but it’s not always healthy because he has lots of medical issues going on and he just refuses to go to his medical appointments. And I’m like but it needs to, you know I know he can say no I don’t want to go, but it needs to be like a certain extent for it cause he really needs to go to the doctor and find out what’s wrong with him cause he’s complaining about stuff all the time but he just don’t want to go to the doctor. I don’t know if he’s scared or anything like that but I think it needs to be like a like a way that you can determine if he can give consent or not. Because he really needs to go to the doctor.

Both Susan and Jessie talked about limiting choices relevant to medical decisions and Jessie referenced a determination of consent process. During this process a person's capability to make decisions is quantified according to normative standards and the ability to make decisions is either granted or withheld at an administrative level.

Another aspect on the prescribed role of direct support professional mentioned during the narrative phase was the implementation of particular aspects of person-centered planning. These descriptions were in response to my question “what do you think about person-centered-planning?” In his narrative Lawrence talked about the mandate of community inclusion. Community inclusion is a term from the local language of service delivery that originated in person-centered practices. Community inclusion requires introduction of disabled people who receive services to their neighborhoods, neighbors, and local businesses.

Lawrence: Community inclusion is good but it’s not as person-centered. If somebody came directly, cause you have more time to fulfill that person-centered instead of you
going out for half hour because you gotta come back and then that’s where the stuff comes back if one person does it all the time then it’s oh that person’s going out all the time. That person’s going out and they don’t help me do this, so you have the conflict of the staff. But if you have one staff who concentrates on person-centered you can reach their, their needs, you can support them and at the same time a lot of things can get done, if you had that.

In Lawrence's account, he explained the expectation that direct support professionals were supposed to implement person-centered plans but pragmatically person-centered planning impeded what he perceived as the role of staff. The expectation that staff were to supervise individuals' interactions with community members could not be carried out since it created conflict between staff members when one person was more willing to carry out that expectation at the expense of other responsibilities. His narrative spoke of the discrepancy between the prescribed role of the direct support professional and the everyday enactment of the role of staff.

**Focus group.** During the focus group discussion, three participants engaged in an exchange during which they listed expectations of the prescribed role of direct support professional that they perceived as outside the role of staff. The group started with a discussion of the requirement of the direct support professional to administer medications and to drive the organization’s vehicles. They described these requirements as possibly consequential in their lives.

Alex: we are in charge of other people’s lives, you know. Literally what exactly are we getting? There are so many ways to ruin your career. You can pretty much not being able to work in schools or (multiple voices). Your life can be ruined over making a mistake for
what 11.15. (laughter) you know you may have gave the wrong medication to somebody and now your labeled you get labeled for abuse. Now you can’t work with the board of education or nothing. And you risked all that for being forced to give out medication, first of all.

Veronica: right

Alex: you’re being forced to give out medication from 11.15 an hour or whatever the hell it is

Susan: it can ruin my driver’s license

Alex: you’re forcing us to do all this and we can ruin pretty much our lives and we’re being forced to do it. I don’t want to give out medication but I’m forced to do it. You’re taking unnecessary risks for no pay

The group also discussed the practice of working with disabled people that may display aggressive behaviors. From participants’ perspective, staff safety was seen as secondary to administrators as they are primarily focused on the safety of the disabled person who receives services over employees:

Alex: your arm could be broken and the guy be perfectly fine chewing on your finger and is the guy OK?

Veronica: does he need help

Alex: you’re always the second thought

(take him to the nurse too, make sure his teeth are alright…laughter)

Danielle: I know it comes with the job
Alex: it shouldn’t be but maybe it affects us helping them out. Maybe some of us are not happy with how much we’re getting paid, now we’re coming to work with a stink attitude because I’ve been working 70 hours for the week just to feel like I have something to survive for the 2 weeks. Cause if I don’t start having a $800 check I can’t make it to the second week. By that first, by that Monday of pay week sitting there trying to figure out how am I going to get this (inaudible…laughter)

Veronica: you work to pay the bills

Susan: but you have to give them extra

During both focus group exchanges, the idea emerged that *staff* were not paid enough and that the expectations of the prescribed role superseded the financial compensation. Financial compensation was not mentioned during the narrative interviews and participants appeared to encourage one another when monetary compensation emerged as an area of discussion. From their perspective, the work that *staff* does on a daily basis exceeds the ordinary expectation of other jobs that are of comparable pay. As Susan stated, “you have to give them extra.” The mandates, expectations, and regulations created the role of the direct support professional but the enactment of *staff* is variant from that role. *Staff* in turn felt they were not recompensed for what everyday practice entails.

**Code B: Everyday enactment of the role of staff.** Code B in the relational construction of *staff* described the everyday enactment of that role. The prescribed role of direct support professional is determined by state mandates and by organization-based procedures and it differed from the constructed and enacted everyday practice. In their narratives, the term *staff* was used by participants to refer to themselves and to their co-workers; however, the role of *staff*
was distinguished from the direct support professional and discussed during the focus group only. This topic of conversation was one of the areas explored when I asked, “what are some things that can affect (or influence) a person’s life?”

During their discussion, *staff* emerged as a distinction from the assigned role of direct support professional. The direct support professional was mandated to comply with rules and regulations which *staff* saw as out of touch with everyday practice. The enactment of the role of *staff* as constructed by service providers was often in conflict with regulations. Regulations were spoken of as barriers. During the focus group discussion, two participants had an exchange during which they contrasted the prescribed role of direct support professional with the impracticality of enacting this role by *staff*. Alex previously mentioned that as direct support professionals they were trained to refrain from developing personalized relationships with the people they work with. The expectation was to maintain a therapeutic relationship based upon service provision; however, the context of service provision requires *staff* to work in the homes of service recipients and personalized relationships became a part of daily life between *staff* and *the guys*. When Alex talked about the emotionally-based relationships that develop within the context of service provision and how this was contrary to the expectation of the role of direct support professional with *the individual*, another participant supported his statement by stating “you can't help it.” Further, other participants responded with laughter in agreement with what Alex said. The laughter appeared to indicate a common understanding among participants that personalized relationships are enacted in everyday practice despite the prescribed role that cautions against such relationships. During Alex's statement, Susan interrupted him to add her own experiences and observations:
Alex: and they tell us not to be too attached to the *guys* (you can’t help it, laughter) but you work for so long they become family you know. You see them like this is my uncle, this is grandpa. (laughter) they become close to you. The same way, you love them. They say don’t be hugging on them don’t give them nicknames but listen

E: but they want that, they want to hug you sometimes, they want to come and give you a kiss. They want you to ask them how’s their day, tell them they look nice, or their hair looks nice, you know you have to give them compliments

*Staff* was constructed on an emotional basis that stood outside of regulatory mandates that were perceived as impractical and out of touch with everyday practice.

During his narrative Alex mentioned what he perceived to be a regulatory mandate, normalization, and during the focus group he introduced normalization as an area for discussion with other participants. Normalization was the regulation that drove services when community-based living was first established after de-institutionalization. Normalization has not been part of the regulatory discourse since the introduction of person-centered planning. Alex is approximately twenty-five years old and has been in the field of disability services for five years, but he described normalization as the philosophy behind service delivery. He argued that although direct support professionals should enforce normalization, the everyday practice did not promote it. Alex offered his interpretation of normalization and how he saw the lives of *individuals* as not living up to his perception of what comprises normalcy. From his account, a normal life is impeded by regulations and treatment plans that require disabled people to do things that do not conform to his interpretation of normalcy. He referenced normalization as relevant to his own standards of what constitutes normal. During his dialogue with other
participants, he stated “who are we to tell them no...” which was indicative that he did not see staff as positioned to enforce mandates and regulations that fall outside the parameters of everyday life.

Alex: it’s not really normalization. We don’t do exactly. We don’t treat them as normal as you want to see them be treated. I feel like the higher ups whoever came up with some of that stuff, you should keep stressing normalization but then you put some much rules to the normalization. How exactly is this being normal? You know you’re saying the guys are allowed to do certain things. You want to see the guy cross the street on the regular and everything but then you’re forcing him like with goals, for example. There’s goals where a guy has to go for a walk every day or something like that. Normally (emphasized) when I come home I don’t want to go out for a walk. Or who said I’m supposed to be in regular clothes all day and I can’t be in my pajamas as soon as I come in. I’m sorry when I go in my house, I strip. I hate wearing clothes. So shouldn’t these guys feel the same way. I mean you come into the house you want to take off your clothes. So who are we to tell them no you can’t take off your clothes or you have to go outside for the walk. You have to let’s say four times a day, it’s not four, three or two (inaudible…. laughter)

The requirements imposed by plans or mandates are not driven by disabled people’s wants but rather appear to Alex to be determined by administrators.

During the focus group, Alex further discussed how direct support professionals were required to monitor and document behaviors displayed by the people they work with. Behaviors is a word from the local language of practice that signifies unfavorable actions. It is often used as
an expression and a person is said to have a behavior. The term behavior is only used to describe unfavorable actions by disabled people who receive services. Unfavorable actions displayed by co-workers, administrators, or non-disabled people are not referred to as behaviors. Behaviors are remediated and changed through behavior plans and guidelines. From Alex’s perspective, he described the guidelines in place as the causes of those behaviors. The enforcement of the role of the direct support professional was the reason for behaviors that were categorized as challenging or in participants' words, restrictions cause the guys to have behaviors. Alex gained support from other participants who reinforced the idea that service delivery is not a natural or normal setting. Another participant in the focus group expanded on the idea of guidelines as sources of restriction and limitation and how it was imposed on direct support professionals to enforce these limitations:

Alex: and then you have to write it on the behavior sheet. Why do you think it happened?

Maybe it’s the fact that you instructed me to asked them 40 thousand times to do something.

Ann: and then all the things they can’t do, the guidelines, they’re crazy. One of my guys he wants to get a tattoo. He watched that thing whatever…in Harlem. He wants a tattoo so they have this whole break down on how it’s not clean. Don’t tell me it’s not clean. It was everything against why he shouldn’t get a tattoo.

Susan: yeah and that’s not fair

Ann: I want to learn how to drive. Well change his mind. Make him go this way. I think that’s just so unfair. I just want to scream from the top of the roof. Y’all so wrong, lucky this is not my son. If my son was like this, you want to set up a certain school. But we got
to do this. Medicaid say do this or we are not going to do this. So we gotta go out this amount of time or we’re not going to get paid. When is somebody going to say it’s not about the money factor right now, it is about the person.

Ann described the difference between staff’s desire to provide services and the ways that direct support professionals were instructed to do so. Staff were expected to change the minds of individuals in subtle ways and enforce agreement and ascent when the individual wanted to do something outside of compliance. This relates to Lawrence's narrative account mentioned earlier in which he described how choices sometimes needed to be “guided” by staff to fit expectations.

The requirements of the direct support professional position interfered with the everyday practice not just in the interaction with the people they work with but by the limitation of interactions due to documentation requirements.

Susan: It shouldn’t always be like get the receipt, oh my God. It’s too much paperwork. There’s no real interaction. You can’t do it the way you really want to do it. You can’t honestly advocate for them the way you want to advocate for them. But when it comes down to the bigger people they don’t really want to hear this.

Alex: Our program gives us a $15. A 15-dollar budget. (background: wow!)

Danielle: Even though they try for it not to feel institutionalized, it still is an institution. Ann: a bunch of small institutions. A bunch of small little houses, little institutions, that’s it. I mean how many times we were talking about a residence and we were having a meeting there and individual’s non-verbal and she was saying that she wants a new comforter set. They tell her no you just had it changed and she’s no, aggressively signing
she wants a new one. They saying you know, wait to next winter. And I’m saying to myself like I’ve changed mine about 10 times. Thank you.

In her discussion Susan talked about staff’s inability to effectively advocate and serve as active agents because of the limitations set upon them by rules and regulations. She mentioned the requirement for receipts, documentation needed in order to allocate monetary resources for activities. She attributed the inability to engage in real interactions to paperwork requirements. These aspects of the direct support professional’s role were perceived as outside the normalized part of everyday life. In natural settings, documentation of behaviors, proof of expenditures, and monitoring of food intake, for instance, are not part of normal life. These practices appeared removed from the daily practices of a household and gave the perception that group home settings held similarities to other social institutions. In her account Danielle equated the limitations imposed by regulations as creating institutionalized settings and that was further elaborated by Ann in her description of group homes as little institutions. Ann gave a specific example of a person who requested a new comforter but was dismissed due to her non-normalized means of communication. Without mentioning normalization, Ann conveyed how she personally had changed her comforter ten times but others saw one comforter per season as normal. The imposition of perceived normality limited the person Ann spoke of and left Ann, as staff, unable to advocate. Ann implicitly expressed that her frustration came from being staff that does not have the power to effect certain changes in the lives of the people they work with.

Susan, on the other hand, explicitly stated that the bigger people or higher-ups, in reference to managerial and administrative staff, did not want to hear about the everyday practices and were more concerned with regulatory compliance. The positioning of managers and administrators as
bigger people or higher-ups was paralleled in the relationship between staff and individuals and these power differentials were relevant in the relational construction of staff.

**Code C: Relational construction of staff.** Code C consisted of participants' accounts, in both their narratives and focus group discussions, that were relevant to the relational construction of self as staff and these statements included any description of disabled people through personalized descriptors, statements that demonstrated common traits between service providers and the people they work with, parallels in everyday experiences including the experience of power differentials, experiences of shared stigma, and the transformation of self as a result of the relationship with the disabled people they work with. Construction and representation of self as staff was relational to the guys they work with. Participants defined their role in the individuals' lives and the role of the individuals in their lives as mutually influential and transformative.

**Narratives.** When speaking of the people they work with, one similarity in these responses was personalized descriptions. These descriptions were relationship-based and revolved around affective connections. From the narrative accounts, some of the personalized descriptions included descriptions of the people they work with as family members, basing the definition of self in relation to them, and descriptions of relationships with one particular person they work with. Mary and Lawrence provided relationship-based responses to my question “how would describe the people you work with” that demonstrated the personal and relational nature of her understanding of the people she works with.

Mary: Well I’ve been working with them for a long time so I think of them as part of my family, which they are…family. I think of them as part of my family.... I think I’m doing
a good job with the guys and we care about each other and I’m just like a part of their family too like they are a part of mine.

Lawrence: It’s like having a brother, sister or family member. You have to get to know them. You have to get to interact with them. You have to learn what their, what triggers them off and more or less have a good connection with them, you know, as far as communicating and all the trust issue comes in there. And that they know that you are there for them and stuff like that because all that incorporates relationship

Jessie provided a relationship-based description to my question, “what do you see as your role when you work with this person?”

Jessie: He actually he likes me pretty much. He keeps asking, he wants me to take him to program or he wants to do stuff with me. So I think I have a pretty decent relationship with him so far…building a relationship. (And how do you see yourself?) I think well I’m still trying to get to know him. I only started working there like maybe a month ago but I think we have a pretty decent relationship so far starting out.

Building a relationship was described as an aspect in the definition of what it means to be staff in everyday practice. Participants described staff as effective when they forged close relationships with the people they work with.

In the process of building a relationship, participants found common traits with the people they work with. Participants described how disabled people are not different from themselves or from other people in general. Katy and Danielle, for instance, described some of the traits in common and the desire to have similar experiences in life.
Katy: It may sound simple but that really works. Just treat them like how you would treat somebody else… We had a lot of stuff in common but you just have to talk to them, just treat them regular. Don’t just block them out like they have nothing to say. You’ll be surprised how much stuff you have in common with these guys. They like the same things that you like.

Danielle: And then there was a night when I was driving her and we went shopping. She said she was like, you know my husband called and she kind of heard the exchange that I would be home soon and everything, and she said I wish I had somebody to love me and so. And it really kind of made me feel and then she started talking about her life and how her son’s father committed suicide. A lot of things I didn’t know and it was like you can be developmentally delayed and then still live the same life as the average person with a different mental capacity.

In her narrative, Ann told the story of a person she works with and the experiences in common that she shared with him and how these common experiences forged the relationship between them. Ann, and the man she described, were able to relate to each other in a mutually transformative way based on these common traits and experiences.

Ann: when his father passed away uhm my sister passed away at the same time so me and him got really close we were sharing and bonding and they at the job they picked me for Everyday Hero and with him and we just been so close we familiarized we’ve had we’ve gone through the same him and him going through this journey and me going through mine helped us helped me understand him more and he was now more he was able to express himself instead of the staff telling him you can’t get on access-a-ride, or you
can’t do this you can’t travel and now he’s speaking up more for himself and I want a cell phone or my hearing aid is broke he gained his independence. He said you know my dad is not here anymore so I gotta take care of me. So working with him that was a great year because I saw him blossom from being so shy and being afraid to this is what I want for my life. So that is a great story as far as the guys making improvements in their own life.

In this account, she and one of the guys went through the same experience of the loss of a loved one. The emotions they shared and the mutual transformation she described demonstrated that interdependence was a trait shared in common as well. The reciprocity in their relationship broke down the dichotomy of dependence and independence and demonstrated relational interdependence that is mutually transformative and developmental. They both changed as a result of their relationship. In her description she mentioned being selected as an “Everyday Hero”. This is an acknowledgment bestowed on direct support professionals who are recognized for their work. As in figured worlds, this type of acknowledgement becomes part of the practices of this micro-culture in which the social identity becomes the individual identity.

Focus group. Through dialogue, another common trait was revealed: the parallel experience of feeling positioned as a person who lacks a voice, power, and the ability to effect change. During the narratives, the individual and staff were spoken about as mutually constructive but staff was positioned as the guardian, caretaker, and the person who knows best. However, during focus group discussion when multiple voices came together, the power differential focused primarily on the direct support professional positioned as voiceless and powerless in relation to managers and administrators. From participants’ descriptions, staff, emerged as a disempowered group.
Alex: we don’t have a real voice cause it’s like the people that write this stuff are people that just sit in cubicles probably researching on-line or whatever they’re saying. They don’t know none of these guys personally. They say don’t generalize these guys but you know you’re giving me a behavior plan for this even the guy for... you get discouraged cause no matter how much you try to advocate; you’re always going to be silenced. And nothing’s really going to change cause we don’t have a voice. We do the most work but you know it’s not like we have a real say.

Mod: who else may feel that way?

Susan: that we don’t have a real say?

Ann: the guys

Veronica: some of them really voice their opinion they can tell management something every day: I want to move I want to move I want to move. And it’s like all right, you don’t want to go here do you? And it’s like

Susan: put you on a waiting list

Veronica: they try to talk them out of it so it’s like we told them you are on a waiting list. It gets to the point of why do I even ask anymore because I’m not going anywhere. It’s like a staff, this needs to change, this needs to change and management is like oh we’ll see about it. They feel like if it ain’t broke don’t fix it.

Susan: if you need someone needs new sneakers, well there’s no money right now. You gotta wait till this. So why do you want me to advocate for, you might as well just wait for the money and then get it. It doesn’t really matter what we say. (laughter)

(inaudible)
Mod: do you think that disables people?
Susan: what, when your opinion don’t matter?
Mod: yes
Susan: yeah
Ann: I have no control of my life. I’ve heard that from the guys. I have no control of my life. If I don’t want to come here, y'all are gonna make me come anyway. This is not what I want to do.
Danielle: that sounds like this one guy here. He always…(inaudible)
Veronica: some of them just want something different. The same routine over and over and over. It’s just like they want different. And we can’t give it to them and we hear it the most. That’s why I think staff, I think it’s great you’re doing this with DSP’s because management hears it but they don’t hear it every day. Like we’re on the inside listening to their stories. I want to move I want to move. I don’t want to go to this program anymore but there’s nothing that we can do about it. We can advocate for you
Ann: but after I do, what’s gonna happen? Nothing

During this exchange, participants drew the comparison to the people they work with and their own inability to act as agents in their lives and effect change. They mentioned that despite self-advocacy and advocacy by staff, nothing changed. Participants also positioned themselves on the inside and management/administration on the outside. Danielle described how they see and hear it every day whereas management does not. Earlier in the conversation, Alex described what he perceived as the behavior or treatment plan writing process that involved a person that was removed from the context of everyday service delivery that sat in a cubicle researching on the
internet without firsthand knowledge of *the guys*. Participants described distance between management/administration and service recipients. Even though *staff* work directly with service recipients, they did not feel like their voices were heard by administrators. Danielle expressed that this focus group gave them an opportunity to have a voice. Within the micro-culture of service delivery, the direct support professional represented a disempowered group that did not have access to power, resources, or a voice and this was also experienced by disabled people who receive services as observed by participants.

Another common experience was shared stigma. Participants discussed instances during which the people they work with were in situations when they experienced stigma effects and participants vicariously experienced it as well.

Veronica: yeah, it kills me because it’s like what are you staring at. Everybody has something about them that’s different like some people one ear might be bigger than the other one like everybody has something about them it’s like why do you stare in these people’s faces like they’re a monster. And it’s like they have feelings too. They know when somebody is staring at them because they might look a little bit different, because they talk different like and it’s bad because we have to know our *guys* so when they’re talking to us we understand what they’re saying. When another person is like ‘what?’ so that bothers me personally.

Danielle: I remember one time I was outside smoking with Raymond and uhm some of the people that live on the block they don’t really like to pass this house so you’ll see them go across the street and then come back across the street

Ann: are you serious?
Danielle: and one day it just really bothered me. And I was like we don’t bite (laughter) and Raymond was like yeah we don’t bite

In these instances, participants interrupted the interaction between the disabled person and the non-disabled person and helped them manage the stigma effects. Veronica and Danielle both described their emotional responses to the stigmatizing comments and they vicariously experienced the effects.

Overall, the data in the theme of relational construction of staff demonstrated the discrepancies between the prescribed role of direct support professional and the everyday enactment of the role of staff in service delivery. The role of staff was constructed in relation to the guys in a mutual process of transformation and development. The role of staff was constructed in terms of personalized relationships with parallels in positioning, exertion and experience of power differentials, and stigma management. The effects of stigma were an instance during which participants were able to perceive the disabling effects of contextual factors. Unlike their language, their ideas and ways of theorizing disability demonstrated a socially contextualized interpretation of disability.

**Theme 3: Contextualized Interpretations of Disablement**

The third theme noted in the data was the contextualized interpretations of disablement. Participants’ discussions revealed that disability was not conceptualized as a personal deficiency, for the most part. Most participants interpreted disability as occurring within a sociocultural context influenced by multiple factors outside the person and there were also references to disability as a socially constructed category. Three codes in this theme included the social
construction of disability, family role in the disablement process, and policy and regulatory systems as disabling.

**Code A: The social construction of disability.** Code A, the social construction of disability, included statements relevant to encounters with social and attitudinal barriers and descriptions of disability as a socially constructed category comparable to other social categories, such as racial minority groups. Statements relevant to this code were only noted from one participant during the narrative phase.

**Narratives.** During her individual interview, Veronica discussed how community members perceive disabled people as having something wrong. She used the words these people to refer to the community members and our guys to refer to the people she works with, indicative of an out/in group binary. These expressions reversed the insider/outsider where our guys showed they belonged with us and community members were outsiders, these people. She stated, the funny thing is, is that these people look at our guys like something is wrong with them and they might be more intelligent than they are. Like they don’t realize like that these guys are really smart, that they can do a lot. Some of them just need help doing certain things. Some of them are just non-verbal, they can do everything for themselves but they just can’t speak. And they think just because they live in one of our homes that like something is really wrong. And that’s what some people don’t realize like (inaudible) some people only live here cause they need help managing their money. So that’s what bothers me. You can’t label somebody just because where they live or just because something is ‘wrong’ (emphasized) with them.
Veronica used the word *guys* in claiming an in-group status that was juxtaposed to the out-group, *community members* who rely on stereotyped notions of developmentally disabled people. Veronica described how disabled people are underestimated because they may not do things in normalized ways, such as talking, and there is a presumption of incompetence when a person does not communicate verbally. Although she used the deficit-based descriptor, non-verbal, she explained how *our guys* defied lowered expectations. Lowered expectation was described by Veronica as a social barrier that promotes disablement.

**Focus Group.** In response to my question “what are some things that can affect (or influence) a person’s life?” none of the participants mentioned disability. Responses to this question focused primarily on contextual factors. Underestimation of capability was discussed during the focus group as a deficit-based misconception that was enacted by, non-disabled people, *community members*. Participants described *community members* as part of an out-group, lacking understanding of developmentally disabled people. During focus group discussions, participants shared stories on encounters with *community members*. During these encounters they experienced social and attitudinal barriers that resulted in social isolation, exclusion, and they observed the disabling effects of labels and stereotypes. One participant, Ann, equated social attitudes towards disabled people to racism.

*Ann:* It’s like racism.

*Alex:* yeah, I say something to somebody, excuse me can I help you? And then you can see in your *guys’* face. Like they actually feel sad.

*Ann:* it’s like they can’t drink the water. Everything, it’s separated. It’s segregation in a sense. It’s like they are not ready yet for that, did you teach them that, do they know how
to sit, can they go into the restaurant. It’s just like that’s how I feel. It makes me want to advocate more for them. It’s like you don’t want to see me outside with them. I go in. (laughter) it’s like a whole other scene. We were in Costco and a lady with her baby she was pulling it all over. Why you doing that for? I’m just, I’m just to the point I’m past it. So I’m just like, I’m not gonna allow you to disrespect them when I’m outside. I can’t take it. It’s like that’s my pet peeve, why are you moving? We’re all in a tight spot. For what? It’s just like, it’s terrible. It’s just because I’m mentally *retarded*, I’m labeled, and I’m slow or whatever and it’s personal for me. I had a sister, I’ve got an uncle, I have some nieces. I was raised, I never shunned it. It was normal to me. Oh something’s wrong with your baby, what’s wrong with her, oh we can get her, we can just get right in and help her to talk, walk. You know it’s all how you treat a person. If you accept me for who I am you will see a difference. But if you put me over there in the corner. This table is only for the whites, this only for the blacks, this for the ‘retards’ right here. That’s how it is to me. That’s how it’s going. It’s like you can’t do this because you don’t have this. They put you in that little category.

Ann's account situated disability in social interactions and imposed limitations. Disability was not the consequence of personal deficiency. Ann discussed the social exclusion of disabled people and how everyday contexts were spaces in which discrimination was enacted and social segregation enforced. When she described her interpretation of people staring or moving away from the people she works with, she alluded to a time when segregation was based upon racial categories. She interpreted disabled as a category similar to racial minority and Ann overemphasized the term *retard* to indicate the pejorative nature of the word. From her account,
the disabling factors were labels and social exclusion. Ann also mentioned familiarity with disabled people on a personal level by listing family members with disabilities. She interestingly used the term “something wrong” when trying to discern disability. To her, differences were *normal* and “walking and talking” were two normalized behaviors indicative that the child was well without noting disability.

During the focus group discussion, another participant referred to social exclusion and attitudinal barriers as the result of a us/them belief among *community members* who were not familiar with disabled people. The discussion on the categorization of *them* was corroborated by other participants during an exchange when they talked about their experiences with social barriers:

Moderator: I want you to go more with that, the whole idea of being one of *them*

Danielle: right, people, people I feel like people shun them. People they kind of it’s, I see it on the train or whenever we go anywhere

Veronica: staring

Ann: it’s like the Red Sea will part, they are like (swoosh sound)

Danielle: It’s funny cause working with them it only make me do more things. Like I’ll be out with Mikey right and people will look at him because, you know he’s so outgoing, but they see the difference in his face so they know something is wrong and it will just bring me closer (laughter) I’m like come on handsome (laughter). It’s like yeah I see you looking so look some more (background: yeah, right)

Susan: yeah give them something to look at
Danielle: Right, and I don’t mind the curiosity cause most people are just curious you know but it’s like
Veronica: it’s the way they react to them (background: right)
Alex: I think also not really knowing
(background: it’s ignorance)

Danielle started the discussion on her observations and experiences with *community members* and how they treat the people she works with. She used the word shun to refer to the attitudes and actions across different contexts. She spoke of one particular person with what Goffman would have referred to as a discredited stigma, an overt marker that was indicative of difference. In this particular case the person that Danielle referred to has Down Syndrome so *community members* were able to see that *something is wrong*. Danielle countered this by describing him through non-disability centered characteristics, such as outgoing and handsome. She defied social stereotypes and reclaimed him as part of her in-group through actions that demonstrated her acceptance, as well as, resistance to social attitudes. She also expressed that she understood their curiosity. Alex elaborated that perhaps curiosity was due to lack of familiarity with disabled people. Lack of familiarity was described as a disabling factor but yet participants also voiced that interactions with family members can have disabling effects.

**Code B: Role of family in disablement.** Code B included statements and discussions relevant to the family's role in the disablement process. Although family can be thought of as having the closest contact with disabled people, participants saw some aspects of family interactions as disabling. It should be noted that level of family involvement varied. Some
participants work with people who have close family involvement whereas others have very limited family contact.

**Narratives.** During the narrative interviews, he absence and/or rejection of family was identified as consequential in *behavioral* displays and overall well-being. The absence of family resulted in an effort by *staff* to take the place of family. Three participants discussed, during their narratives, the effects of lack of family involvement. The following were responses to my request for participants to “tell me about a person whose story you would like to share.”

Danielle: I think she’s sad. I don’t think she’s…I think she’s always looking for approval, not in the way like someone like Teresa but like I feel she’s always looking for…she never thinks it’s good. She’s always asking ‘you like this?’ I also feel like her family doesn’t give her the type of love that she deserves so you know I don’t think she’s happy at all.

Mary: Her family, you know, they don’t come see her and she misses that…uhmm, yeah...Her life is good. She goes to program, she likes that. She goes to the store around the corner to get her coffee. She likes her cigarettes; you know uhm she misses her family. She has a sister but ah you know she doesn’t come see her a lot. Yeah but she talks to and tries to help the other individuals here and staff.

Lawrence: You know what I’m saying. He would tell me things like he wished his mother and father would come more often or that they would come and see him or he would go over there and things like that. So and then he had issues sometimes where he would tell me his legs were bothering him or his walking or whatever. Any little thing that he had a problem with a lot of times he would discuss with me.
In his narrative, Lawrence started to allude to staff taking the role of family. He first spoke about this particular person's desire to see his parents more often. Immediately after speaking of his parents, Lawrence discussed how he person would speak to Lawrence about medical concerns or “any little thing”. Lawrence became the stand-in for the parental figure who he perceived the person would have gone to with similar concerns. Susan also saw the role of staff as serving the function of family. She listed some of the things that family members provide one another both materially and emotionally. Susan stated: “I think they rely on staff to be, some of them, to be their family. And you know when staff comes in and brings them a little something or do their hair or do something for them that really makes them feel good and that’s the only family they have, really, we’re just not blood.” When family was not present, staff took on the role of family member.

When there was family present, there was an expectation of family involvement in service delivery as is mandated by person-centered-planning in which family is part of the circle of support. However, participants described interactions and observations that they perceived as part of a process of disablement. From the narratives, the idea that family was a disabling factor was discussed by four of the nine participants. The effects of family involvement had different consequences and one of the effects discussed was the infantilizing of disabled adults by their parents. Alex, for instance, referenced a Rick who he perceived was infantilized by his parents both during his narrative and then again during the focus group. During his narrative, Alex stated:

I would say Rick would be more challenging because he’s like a 20-year-old infant. I mean I feel like, not to say his parents didn’t do a great job, but I feel like they treated
him so much like a baby now it’s kind of hard to get him to do you know stuff age appropriate. I mean from using the bathroom or, you know, sucking his thumb and wanting to bite everybody. It’s like their parents, his parents, condone it. They think it’s all right for when he bites people.

The disabling effects of certain family relationships were an area of discussion that Alex and other participants agreed upon during the focus group.

**Focus group.** Family involvement was an area of discussion that arose in response to my question “what are some things that can affect (or influence) a person’s life?” Family was the first answer simultaneously stated by two participants. The conversation immediately became about the effects of family rejection:

Moderator: OK, what are some of the things that you think can affect or influence their lives? What are some of the things that have an impact on them?

Jessie/Veronica: Family

Moderator: what about family?

Veronica: they want closer relationships with their family. And I think their family thinks because quote unquote something is wrong with them that they can’t bring around, they don’t want to be around as much, and they don’t realize that that is so hurtful. That might be the reason for their behaviors because they’re not getting the love that they want and should get.

From this exchange, family rejection was attributed to disability or in participants' words “quote unquote something is wrong with them”. Veronica implied, by using the expression quote
unquote, that something wrong is a culturally embedded idea that she disagrees with. Alex then elaborated on his perception on the disabling effects he has encountered:

Alex: I mean I think some of these families do more damage than help cause I mean for example some of these guys...like I have one guy Rick his family treats him like a baby so you know he never really gets the chance to learn you know this how you feed, or biting is wrong and stuff so we’re so pressed to try to always you know biting is not good you’re not supposed to bite people but as soon as the family comes around oh it’s all right he can bite me it’s OK (laughter). The mom, he bit the mom’s hat and like start pulling on her wig and she thinks it’s cute.

Ann: he’s not a baby, he’s a grown man

Alex: he’s a grown baby and that’s because the parents didn’t teach him. The parents kept treating him like a little kid, never gave him the opportunity to grow, gave him a better opportunity not to say normal but at least not to have as much problems as he has now. For us to try to get him off the biting habit is hard because you know it’s what they are doing and we are doing are detrimental to each other. It’s like, you know, try so hard to show that biting isn’t good but when the parents come around they think it’s all right for him to bite them and stuff like that, so. It’s kind of hard to work with parents and also try to do your job at the same time cause they can come in and swoop and change whatever they feel like it, whenever, so…yeah...

From his descriptions, the parents' actions not only disabled Rick but they also currently prevent staff from providing what Alex felt were suitable services. He described Rick as a “grown baby” contrasting that Rick is a man but yet his behaviors were that of a child. Alex attributed Rick's
child-like behaviors to the parents' infantilizing, therefore, disabling him. In this account, the work of service provision was in tension with parents' behaviors and their influence on service delivery.

When Alex spoke of parents interfering with service delivery, he alluded to efforts to include families in the determination of services, as mandated by person-centered planning. During the focus group discussion another aspect of parental involvement emerged. In their discussion, participants also described parents' interactions with their children not just through infantilizing but also through spoiling their children. This set of actions was seen as a hindrance in that it failed to maximize the abilities of their developmentally disabled children and was described as setting them up for failure. From these interactions among participants, it seemed that they expected parents to teach their children normalized behaviors that would maximize independence. Failure to teach normalized behaviors meant greater dependence and failure for the developmentally disabled person:

Ann: They don’t want to hurt their feelings but they’re hurting yours. And another parent complains, I’m not coming I’m stressed because Joey knocked me out last night and my husband came home what? when I woke up he would have been out of the house. You let this go on and on and you’re teaching them this is OK (right)
Alex: like certain things I feel the parents also feel guilty. (yeah) With all the feeding especially a lot of these parents over feed the guys
Ann: yes, yes
Katy: just to keep them happy
Ann: yeah, it pleases them
Alex: they feel bad. They feel like it’s their fault for having a kid like this.
Ann: but if you wasn’t drinking, smoking, and what…if you feel sympathy as a mother, if I didn’t do anything, God knows, while I was carrying this child and this child came out whatever I don’t have no guilt, this is God’s way. So I’m not going to sit here, you want me to treat you normal, you gonna be treated normal. But a lot of parents can’t separate that they feel like they have to do this because it is their fault.
Veronica: it’s like XY, he’s the only one that goes home you know so we know when he goes home he’s in front of the TV with the remote, eats whatever he wants, and doesn’t have to do at home…like he’s parents will say oh he doesn’t have to do anything at home. When he comes back to the house he wants to do nothing and it’s hard because it’s like we don’t want to tell him you have (emphasized) to do you have to because he doesn’t, he has the right to not do anything. But it’s like you have to do something. It’s like you taking him home and just having him relax and that’s his getaway or whatever but you can’t have him just relax all the time at home, just eat, cause when he comes home he’s going to expect that and it’s hard for us, it’s very hard for us.
Ann: you set him up, you’re setting him up for failure.
Lack of involvement was also described by participants as a disabling factor in that it caused, in their view, behavioral concerns. They described what they perceived as causality between lack of family involvement with behaviors that they described as challenging. Whereas some parents were described as involved to an extent that it interfered with service delivery, other parents were described as removed from their children’s lives and this too resulted in behaviors labeled challenging. Participants described some disabled people as left in institutional
settings. Some participants described placement in residential services as a cause of challenging behaviors:

Veronica: I don’t think, well not just autism, like in general I don’t think we need to find a cure cause I think some of these behaviors come from what their families have done to them. Cause if I was shipped away cause I looked a little bit different because I’m not acting like somebody my age. If I was shipped away, I would have behaviors too. What’s going on that you’re shipping me away? So that’s what they’re used to. If they were brought in an institution or sent away to an institution, of course they’re gonna act like that and they move into these houses and they’re getting medicated. They may not even need medication. They might just need love. So you’re saying they need this medication, they need this, they need that. No, they need their family around (inaudible, hmm mmm)

Veronica's account does not situate disability within the person but rather in the consequences of institutional settings, perceived rejection by family, current residential settings, and the use of psychotropic medications. The use of medication was mentioned differently at other points during the focus group discussion. Following the initial question, “do you think that the people you work with are very different from other people?” Susan distinguished the people she works with from non-disabled people through the assumption that disabled people require medications. Responses relevant to medication use, however, are further discussed in theme 4 code A.

Another social aspect brought up during the focus group discussion relevant to families was the effects of the social system that maintains disability through limited financial resources. Ann mentioned that disabled people were forced into unemployment because they would lose their financial support if they earn more than a predetermined amount of money alluding to a
social and economic disabling factor. This appeared to be based upon the assumption that disability was equivalent to dependency and this was enforced by a financial system that was designed to disable people. So the social system played a part in the disablement process and this was maintained by families that became reliant upon financial assistance.

Moderator: so I hear that family can disable? (yes, big time) What other things disable them?

Ann: Society in a sense. You can’t get this job because if you work in McDonald’s, Brian, your check is going to be cut mm mm going to shut that down. So we, we hinder them too in a sense in this society. We give you this SSI check and you going to do A B C with that but you can’t go get a real job, you get a job that’s it for your check. So it’s a money factor too with the family. They make their children stay to a certain point too cause my check is going to get messed up, my rent is going up. He ain’t doing this so that’s a big factor too.

Disability was described by participants as a consequence of social and contextual factors that limited employment for disabled people. In turn participants described their role as mitigating the effects of disablement. They devoted a great deal of discussion to the effects of family on people's abilities, as well as, social and attitudinal factors that prohibited full participation in the community. These social and familial factors in the disablement process were spoken about overtly and participants identified them as things that disable people. However, participants also spoke about policies, rules, and regulations and in their discussion it appeared their interpretations of regulations too played a part in the process of disablement. Further, not only did policies disable the people they work with, policies also inhibited participants from
what they identified as their role in service delivery. This disconnect between policy and practice was described as disabling.

**Code C: Policy-Practice disconnect as a disabling consequence.** Code C in the third theme, included descriptions on the effects of policies and regulations on the limitations of everyday choices, statements on impracticality, and restrictions imposed by certain policies as contributing to a disablement process. During the narrative interviews, nearly all participants with the exception of one person, had a initially positive view of person-centered planning. During the focus group, however, participants saw plans and mandates based on person-centered planning as disabling. They engaged in discussion on the consequences of mandated *community inclusion* and levels of supervision that were determined in a top-down manner. Policies were described as restrictive and as limitations on activities and autonomy.

**Narratives.** In response to my question “what do you think about person-centered-planning?” most participants expressed a favorable view. They provided their interpretations of person-centered-planning, as follows:

Katy: I think it’s good cause at the end of the day if the guys don’t like it, it won’t work. It has to be something they enjoy. Even something simple like getting a cup of coffee if they like it or to go to places they enjoy or on TV watch something that they like. If they don’t like it, they are not going to do it.

Susan: Person centered planning, I think it’s a good thing it’s around, it’s goal is basically for that one person to maintain or something that will help them be a better person, more independent person. I think it’s I don’t really I don’t really (you can say what you think)
that’s the plan where someone writes it up I think it’s better when a person has one staff with them to help them with certain things. I don’t think that all the time the way the person centered planning is written up is a good idea. I have my nays and my yeas, basically. (Tell more what.) Uhm I think it’s easier to deal with this population more one on one not so much of just writing everything it seems to me that when they write the different things although it may be specifically for that person but it’s more generalized it’s not really for that one person they are thinking about other clients and different things that happen and they kind of putting it into one I don’t really think that most of them are for that one particular person

Ann: person-centered-planning I think it’s to each person but at different levels. Because we all can say OK she may want to learn how to cook but she’s non-verbal and she can’t communicate with you but how do you know. But so when I open up the magazine she you know looks at this like ‘ah’. So it’s different when you’re dealing with somebody who is telling you listen I want to do A, B, and C. So person-centered-planning we have to be careful to who we work with or we’re just generalizing it so person-centered-planning is good in some ways if the person can understand it and is able to move and work with it.

Jessie: It’s a great thing because not all the individuals are the same. So you know we want different goals and different things for different people.

Alex: I think it’s better, it’s good cause a general plan for everybody I mean you’re not really helping that certain individual cause everyone is different.

Danielle: I don't know much about it.
Veronica: I think that’s very important. I think we should definitely focus on things that they want out of life like what they’re interested in and getting them to do what they want to do. Like, what they want out of life. So I think that’s very important.

Mary: The plans are pretty good, like I’d say you know, it fits them. They’re good. At this time, I think they meet their needs.

Lawrence: Oh, Person-centered, ah. I believe that written down it sounds perfect, yeah. The reality you give a person I would say a great deal of your work but it’s not going to be 100% because when you have 12 different individuals and you have someone who likes to go maybe to basketball you have another guy that likes bowling another guy that does this and that. We really have the person-centered where we do read the things but not to the point that I think it should be met. I have an idea; do you want to hear my idea? Person-centered to me because of the staffing, you only have three people with twelve people. To me I think that there should be one person, to reach that person-centered, should know all the individuals and if you have that one person that their job is just to go in the comm [community].

Initial responses from participants supported person-centered planning but as they began to talk about it and attempted to describe it, they noted the negative aspects. They talked about the impracticalities when implementing this approach and they also mentioned how person-centered planning may not be an approach that is effective for everyone. Participants had a general understanding of person-centered planning, with the exception of Danielle who stated she was not familiar with it. However, they did not appear to know about the process of creating a
person-centered plan. Some of their definitions of person-centered planning appeared to be based upon their interpretations of the words person-centered.

**Focus group.** During the focus group person-centered planning was not referenced directly but aspects of individualized planning were critiqued. Two aspects that were critically discussed were the determination of levels of supervision and compulsory *community inclusion* activities. These were seen as developed by administrative and clinical professionals, in a top-down manner, without consideration of everyday pragmatics. This approach would appear to be a misapplication of person-centered planning since direct support professionals were not involved in these determinations or plan development. Even further, it was argued that the disabled person may have been excluded as well since the mandated services may not match the person's preferences.

Determination of supervision level was spoken about as a limitation imposed by restrictive plans and policies. Some *individuals* were assigned one direct support professional or even two direct support professionals, in certain instances, in order to ensure health and safety. This level of supervision was seen as restrictive when coupled with everyday pragmatics, as it limited the types of activities that the person was able to participate in; therefore, further isolating this person.

Alex: Weekends it’s usually where we try to take them out and stuff like that but even that’s hard since he’s 2 to 1 in the community. So usually to get to, the extra staff cause we have what three 1 to 1’s in the residence...I'm thinking…1 to 1 is definitely more challenging than normal individuals I would say that. Cause it’s you have to do so much
more and it’s with you try to respect their privacy but then again you are told that you 
know sometimes that 1 to 1 kind of they really don’t have their privacy. It sucks, 
sometimes they’re using the bathroom and you have to be right next to them. And I have 
a big thing about that. I feel like they should have way more privacy then they are 
supposed to.

In his discussion Alex once again referred to people he works with by their level of supervision. 
People were talked about as two-to-one's or one-to-one's. The greater level of supervision was 
indicative of the greater challenges the person may pose. He also mentioned that people 
requiring these levels of supervision are not given privacy, in compliance with certain one-to-one 
protocols, but in practice staff saw it as unfair to deny someone privacy in situations such as 
using the bathroom. Alex also talked about how certain services were out of touch with everyday 
practice and described them as prohibitive in choice making. He again alluded to normalization 
and saw service delivery as something that is outside the normalcy of daily living. Refusal to 
complete or receive a service was then categorized as a challenging behavior that had to be 
written down and monitored. From his account, the challenging behavior was not caused by an 
internal deficiency of the person but rather by the service delivery system that had expectations 
and demands that were not congruent with daily life.

Alex: it’s not really normalization. We don’t do exactly. We don’t treat them as normal as 
you want to see them be treated. I feel like the higher ups whoever came up with some of 
that stuff, you should keep stressing normalization but then you put some much rules to 
the normalization. How exactly is this being normal? You know you’re saying the guys 
are allowed to do certain things. You want to see the guy cross the street on the regular
and everything but then you’re forcing him like with goals, for example. There’s goals where a guy has to go for a walk every day or something like that. Normally (emphasized) when I come home I don’t want to go out for a walk. Or who said I’m supposed to be in regular clothes all day and I can’t be in my pajamas as soon as I come in. I’m sorry when I go in my house, I strip. I hate wearing clothes. So shouldn’t these guys feel the same way. I mean you come into the house you want to take off your clothes. So who are we to tell them no you can’t take off your clothes or you have to go outside for the walk. You have to let’s say four times a day, it’s not four, three or two (inaudible…. laughter) and then you have to write it on the behavior sheet. Why do you think it happened? Maybe it’s the fact that you instructed me to asked them 40 thousand times to do something.

Ann: and then all the things they can’t do, the guidelines, they’re crazy. One of my guys he wants to get a tattoo. He watched that thing whatever…in Harlem. He wants a tattoo so they have this whole break down on how it’s not clean. Don’t tell me it’s not clean. It was everything against why he shouldn’t get a tattoo.

Susan: yeah and that’s not fair

Ann: I want to learn how to drive. Well change his mind. Make him go this way. I think that’s just so unfair. I just want to scream from the top of the roof. Y'all so wrong, lucky this is not my son. If my son was like this, you want to set up a certain school. But we got to do this. Medicaid say do this or we are not going to do this. So we gotta go out this amount of time or we’re not going to get paid. When is somebody going to say it’s not about the money factor right now, it is about the person.
Regulations were described as limitations on behavior and prohibitive in the expression of autonomy and independence. Participants presented the direct support professional as the enforcer of restrictions despite their own apprehension. *Staff*, however, was spoken of as an active agent that attempted to effect change in the lives of *the guys* by focusing on and knowing them. Regulations and financial restrictions were spoken of as secondary to the person. The direct support professional, however, was the actor that had to provide services within the parameters of mandates and institutional demands. The different voices and ways of speaking were noted throughout their interactions and discussions.

**Theme 4: Enactment of Deficit and Social Discourses**

Data analysis on the ways of speaking and discursive approaches of participants revealed the enactment of various disability discourses including deficit-based and socially contextualized language. Deficit-based discourses were enacted during individual narratives however during focus group discussions there was a more socially based interpretation of disability. With the exception of one participant who maintained more medical/deficit based definitions of service recipients throughout narrative and focus group discussion, other participants appeared aware of deficit-based language during the focus group.

**Code A: Deficit-based and medical discourses.** Deficit-based discourses included statements on *functioning* levels, statements that situated disability within the person, and statements that described *challenges* as inherently caused. Although deficit-based words were used during the focus group discussion, during narratives these words were used to provide descriptions of people. During the focus group, deficit-based words were used in their
discussions on language and labels and not necessarily as descriptors of personal deficiency. Statements coded as deficit-based discourses, where deficit is a property of the person, were evidenced only during the narrative interviews.

Functioning level was referenced during narrative interviews and functioning levels were spoken about relevant to a person's ability to make choices. Functioning level was also seen as relevant to a person's degree of disability and quality of life. People that were considered lower functioning were not afforded the same opportunities to make choices and disability was described as situated within the person as an individual deficiency. Social limitations and barriers were described as relevant to people with mild disabilities or high-functioning individuals. During his narrative Alex responded to my question, “what are your thoughts on people’s abilities to make choices and decide for themselves?” by mentioning a person’s level of functioning. He also listed the person's diagnosis to validate the role of staff in determining what is best for the people who “don't know what is best for them.”

Alex: Sometimes the choice, some individuals I guess have their own choices isn’t really the best thing because usually I’m not saying they don’t, sometimes they don’t know what is best for them. So you know, so some want to eat inedible objects but you know it’s up to say to say you know what it’s not all right for you to do you know you’re not taking that choice away from them but you want to keep them safe at the end of the day. And other times some may have dysphagia and they want to eat their whole food but you know you have to chop it up or they might choke so sometimes choices are good but as a staff you should know that choice in this situation isn’t, you know, you don’t have a choice in this situation. It sounds messed up but sometimes it’s the truth.
From his account, some people are able to make choices but other people are unable to because of their diagnoses. The choices they could potentially make may compromise their safety because they lack the abilities to make the best choices.

Alex’s response can be contrasted to answers he provided earlier in his interview. In response to my first question “how would you describe the people you work with?” his description started with non-disability centered descriptors, “young, full of energy” prior to the disqualification of challenging. The initial description of young and full of energy were not necessarily positive personality traits but sources of additional work for staff.

Researcher: How would you describe the people you work with?
Alex: Young, full of energy and challenging
Researcher: Tell me more
Alex: Uhm I’m used to working with more older individuals so now the guys I work with now are all young guys in their 20’s so it’s like from where they usually don’t have a lot of energy to now everyday it’s a lot of running around, yelling and stuff. It’s not it’s more, it’s not as relaxed as the other guys. You know, more challenging than usual. Way more behaviors. You know most of the guys when they get older you know there like I’m sick of this, I’m not, I don’t want to, I don’t feel like yelling or biting and all that and now every day you don’t know what you’re dealing with when you come on shift. You may have a day where everybody is calm or have a day where you’re being attacked and somebody is biting you. So it’s different.

Deficit-based language was also used to describe the motivations of disabled people’s actions or behaviors. In her narrative, Susan made a distinction between people who are able to
control their emotions and behaviors and she described as normative among disabled people the use of physically aggressive behaviors as a means of communication. Their inability to control their emotions is relational to a normal person and medication, from her perspective, was what separated a disabled person from a non-disabled person. Emotional instability was described by Susan as ordinary among the people she works with, making them unpredictable and aggressive.

Researcher: How would you describe the people you work with?

Susan: Challenging

Researcher: Tell me more

Susan: The people I work with have… I believe, working with them is very challenging because you don’t know how your day is going to go from moment to moment, second to second, I should say.

Researcher: Tell me more, how

Susan: With their different, I guess you’d say, mood swings one minute they are OK and you can talk to them and reason with them and the next minute they’re cursing at you, telling where to go, die, things of that nature.

This description portrays challenges as a consequence of the behaviors. The level of unpredictability is caused by the person's behaviors which creates a more difficult job.

Deficiency situated within the person is seen throughout Susan's accounts. Another example, was when she described psychotropic medication as the factor that differentiates developmentally disabled people from non-disabled people. Medication was also the vehicle that enabled people to control their emotions and respond in socially acceptable ways that complied with normative behaviors and functioning. Throughout Susan’s narrative, it is noted that she uses
the word *them* when she refers to disabled people, an indication that she sees disabled people as part of an out-group. Further, people she defined as *non-verbal* were perceived as more likely to display behaviors identified as *challenging*. Susan made the following statements during her narrative:

I guess the difference is that they are on medication and we’re not you know to control maybe their emotions. Maybe they’re non-verbal so they can’t speak so maybe they’ll throw a chair or you know maybe walk up to somebody and hit them that’s their way of expressing that they’re upset.

Maybe they can’t control their feelings or emotions as well as a normal, I guess you say, person or a person that doesn’t have to take any type of medication to keep them calm.

With their different, I guess you’d say, mood swings one minute they are OK and you can talk to them and reason with them and the next minute they’re cursing at you, telling where to go, die, things of that nature.

Another participant, Katy, started her description without mention of deficit but then also described the people she works with as challenging due to their behavior.

Researcher: How would you describe the people you work with?

Katy: Like my *guys* or like the whole building in general

Researcher: The people you work with

Katy: Oh…funny, caring, challenging at times, uhm

Researcher: Tell me more about that

Katy: Cause I mean some days some days it’s fine like there’s no behaviors no issues but then others and it’s not just always behaviors come from sometimes like what happens at
home and they bring it here and like we know how to do it if we are having a bad day like we can stay to ourselves and not just say nothing but they don’t know how to express themselves or some of them don’t know how to express themselves so they lash out and it’s most of the time it’s in a negative way but if you know your guys like you know how you know to help them or say and they feel if they trust you they’ll come and talk to you and tell you what’s wrong stuff like that but sometimes that don’t even work so it could be challenging at times.

Katy, however, attributed challenges to an interaction between environmental factors and personal disposition. Katy did not situate behaviors as emergent from within the person but described contextual and environmental factors as contributing to the occurrence of behaviors. Events at home, along with an inability to express themselves were identified by Katy as causes for behaviors that may pose a challenge. Katy also drew parallels between the people she works with and non-disabled people. She explained that everyone has bad days but non-disabled people are able to cope with those bad days in more effective ways. She then described disabled people’s inability to cope with negative contextualized experiences due to their inability to express themselves. Although the cause is located externally, the inability to respond to it was a personal deficiency.

**Code B: Socio-culturally embedded discourses**

Socio-culturally embedded discourses included statements that identified contextualized factors as disabling. Narratives described disability as a personal deficiency. During the focus group, however, deficit-based words were used but theories on disability and descriptions of disabled people were socially-contextualized.
During the focus group discussion, participants used socially contextualized definitions of disability. Unlike Susan, the other participants did not describe disability as situated within the person but rather, described disability as difference not necessarily deficiency. Disability was described as a different way of being, learning, or communicating. Discourses on disability as difference, not deficiency, were labeled as socio-culturally embedded and included statements on disability as difference, statements on acceptance, and references to aspects of neurodiversity. Although participants never actually used the word neurodiversity, they alluded to aspects of it. The word neurodiversity seemed like a technical or medical word and all participants were unfamiliar with it. Despite unfamiliarity with the term, during the focus group discussion, participants spoke about topics relevant to neurodiversity such as acceptance, difference, effects of labels, and the negative implications of curing developmental disability.

Katy: I think society is so quick to put a label on stuff. They’re not walking at ten months, something’s wrong, they’re not talking, something’s wrong. I know my brother he didn’t start talking till he was 5 and this was at that time we were in Trinidad this was years ago. I think if he was up here they probably would have labeled him as auti, an autistic person, child. My father didn’t start talking properly until he was 11. And this was way back in the days in Trinidad. So imagine now he would have been labeled so quick. Until he was 11, have a proper all out conversation. And my brother until he was 5, he was doing everything. He was smart. He knew what he wanted, but he was like (makes grunting sound) and getting frustrated cause my mother was like what are you talking about. But and she that was normal to her cause back then there wasn’t all these different levels and this and that. It was never nothing like that.
Katy talked about cultural differences in the definitions of disability. She also discussed how the imposition of labels has disabling effects and contributes to the creation of the category of disability. She spoke of development occurring differently. She referenced her family experience as evidence of difference not necessarily implying pathology. Although her father and brother were unable to communicate verbally as children, it was not viewed through the lens of pathology.

When asked about their thoughts on the readings pertaining to neurodiversity the discussion turned to disability as difference, and acceptance versus awareness. *Curing* autism, and other developmental disabilities, was also discussed from various perspectives.

Susan: it’s a different way of learning something, maybe a little bit slow?

Ann: what is it when people read backwards what is it called?

(dyslexia)...OK so, if you put them in a room nobody can separate them. It’s just a way of learning. Everybody learns different. At a different speed. I’m more hands on. I can read and learn too but you know I’m a visual learner you know so everybody has different ways of learning things. So….

Katy: I have a guy in my class, he’s autistic. He doesn’t write but he can tell you the ABC’s, count from 1 to 50. And just start 1…and you won’t think so because he’s autistic but it’s a different, that’s he’s way of learning (yeah). He can’t write it but he can tell it to you. And I think autism, I’ve learned, they each have their own way of doing things (yeah). And their different than…

Susan: and they probably don’t want to change
Katy: It doesn’t mean that they’re slower than others, they just, cause he knows how to count, he’s very smart. He knows his name, he knows where’s he’s at, if you ask him he can’t write it but he’ll tell you

During this exchange, Susan explained development as occurring at a slower pace which complies with a cultural misunderstanding of developmentally disabled people as slow. Katy and Ann, however, countered her argument and used dyslexia as an example of neurodiversity. She described dyslexic people are indistinguishable from others aside from a different way of learning to read. Katy's counterargument relied on an example from her experience from her work and she described an autistic man who has skills that perhaps are not expected if he is viewed as deficient. Although he is unable to verbally communicate, he is able to write. So the emphasis was difference not deficiency. I then asked if words or the way that disability is spoken about makes a difference and the conversation turned towards acceptance and curing disability.

Moderator: (in reference to the language of neurodiversity) Do these words make a difference?

Jessie: There is a difference cause autism acceptance means you’re accepting the person because they’re different. Awareness means you’re teaching everybody about the different kinds of autism……..

Veronica: more so on acceptance. I’ve known kids that they have spoken then one day that’s it like they just stop so if people don’t know where it comes from you just have to accept it. Like this is happening, understand it, don’t just go out there oh well ‘we need to find a cure, we need to raise money and find a cure’ I mean come on.
In their discussion, Jessie and Veronica saw acceptance as going further than awareness. They argued that acceptance validated the person. The person does not need to be changed, fixed, or cured. Veronica in this instance was responding to a statement made by Danielle who thought that cure attainment research would maintain disability as a relevant topic. Finding a cure emerged as a contentious conversation during the focus group that lead to moments of agreement and disagreement without resolution.

**Code C: Lexicon of disability**

Throughout the process of data collection and analysis, particular attention was paid to the words and terms used by participants. The language used by participants provided insight to the discourses enacted and created what I interpreted as a lexicon as part of the local language within this particular service delivery system. This lexicon was a local language specific to this field of work and this particular organization. The lexicon of disability embodied the co-occurrence of medical and socially contextualized discourses. Further, participants began to discuss and attempt to make sense of certain words and during the focus group, there were moments of agreement, disagreement, and re-conceptualization of particular words that are part of their everyday practice.

A word that emerged as part of the everyday lexicon, the local language, within this service delivery system is the reference to people who receive services as *the guys*. *The guys* was often paired with the ownership quality of *our guys* or *my guys*. Within the narrative interviews *the guys* was said a total of twenty-four times and it was used by all participants. During the focus group discussion, it was said sixty-five times. *The guys* was the expression used by staff in
a personalized way that was indicative of a close relationship based upon mutual trust and understanding. *Individual* was the language of the direct support professional that maintained an emotionally neutral relationship based upon service delivery and compliance with policies and regulations.

In reference to descriptive words used to define developmentally disabled people, aside from *guys* and *individuals*, client and population were also used but at lower frequencies. Client and population were used by one particular participant, Susan, to describe disabled people who receive services. Susan also provided answers and responses that were more medicalized and deficit-based than other participants.

Two other words that appeared throughout the narratives and discussion, that participants appeared to have a common understanding of, were *challenging* and *behaviors*. Challenging was used by four and behaviors was used by five of the nine participants during their narrative interviews. Challenging was used to describe circumstances that were difficult to manage and most often challenges were attributed to *behaviors*. The word *behavior* was identified as something that someone has instead of something someone does. Participants described the people they work with as *having a behavior* when the person responded in a manner that was seen as *challenging*. Behavior as part of the local language of everyday service delivery is used exclusively to describe behaviors that are unfavorable and displayed by disabled people.

Another recurring word used by several participants was *functioning*. Functioning was contentious at times as some participants disagreed with its usage in the description of people's abilities. Participants described functioning as the cause of bias when working with someone as
there were lowered expectations when functioning was described as low. Functioning was stated by participants nine times during the focus group. The conversation on functioning emerged during the focus group when participants attempted to construct a way of describing the people the work with.

Susan: I would say mentally disabled.

Veronica: When people ask me what I do I just say I work with people with developmental disabilities but these people like (inaudible)

Jessie: I work with adults with mental disabilities

Alex: it’s a mental disability

Veronica: yeah they be like really well what is it that you do?

(yeah, laughter)

Moderator: do you think people don’t know what it is?

Veronica: but I would never call them retarded because these people are really smart like (very) when you think retarded you’re thinking somebody who’s like, I’m so sorry, like duh like they don’t know anything but these people…

Ann: like profound, profound retardation. That’s what I would call retarded but I like used to call my sister, she’s special, she’s slow. And she was. And by society’s standards she was. She was in a Special Ed her whole life, graduated from high school with a special diploma. My uncle also but we never treated them differently.

Veronica: and they shouldn’t be

Ann: yeah

Susan: that’s right
Moderator: what are some of the other words that are similar to profound
(severe, inaudible, moderate)

Moderator: What else? Say it again Jessie

Jessie: low-functioning, high-functioning

Moderator: low functioning and high functioning, what do you think of those words?

Ann: I don’t like them

Veronica: I don’t like them either

Moderator: what’s wrong with the functioning?

Ann: you’ll hear some of them say I’m high-functioning (yeah, mmm mmm, inaudible)

…I know my rights (laughter)

Alex: when we use retard, we don’t think of these guys. we don’t put retard on these guys in that category. We put somebody…

Moderator: do you think other people do?

Alex: no, I don’t even think other people do. I think when they use retard they just think of somebody really really dumb. Cause that’s how I use retard. (inaudible, laughter) You don’t think of these guys when you say retard you don’t you think of a real dumb person saying something that’s really dumb.

Ann: like my son did something is so retarded, why did you do that?

Alex: yeah, it’s not like I’m saying…oh thinking of one of these guys, I’m just saying you did something really dumb

Susan: that’s true though

Alex: everybody can be that
Danielle: that doesn’t make it right, that doesn’t make it right. But I know, I understand how easily it can be like just how it comes off your lips

Moderator: do you think these words make a difference? Does it make a difference if they are consumer, retarded, individual?

Ann: it’s a label (it’s a label)

Danielle: it’s all about your place in society because…

Ann: your category, we’re all up in categories: middle class, poor, rich, it’s everybody is…

Danielle: (inaudible) it was a midget now isn’t a little person

(laughter) to me it’s all about labels and your place in society

Moderator: what do these labels do?

(multiple voices)

Veronica: Especially in some of the residence where let’s say high and low functioning together they be like ‘oh I can do more than them. No, you don’t do that. Like everybody is here for a reason. Everybody is here for a reason.

Ann: everybody here needs assistance with something

Veronica: Exactly and when we say high and low functioning one may be considered high functioning and the other low functioning but the low functioning one can do more than the one who is high functioning, it’s crazy like you might understand better you might be able to do more like physically. But this person may be way smarter than you.

(mmm, mmm right, inaudible, multiple voices)
Although participants used some deficit-based words, their views and ways of conceptualizing disability were generally based upon contextual factors that demonstrated that disability was seen as a socio-culturally embedded category and not situated exclusively within the person.

**Code D: Co-construction of discourse through dialogue**

Code D is only captured during the focus group since statements that are part of this code involve dialogue between at least two or more participants. During the focus group discussion, disability was constructed as a process influenced by multiple factors that can alter the degree of disablement. Disability was defined as relational to relative abilities, not normalized behaviors. Normal became a word of outsiders who were not familiar with developmental disability.

Despite agreement on the abilities and the underestimation of the people they work with, there were moments during the focus group that participants did not reach agreement particularly as it related to what words or terms they perceived as appropriate.

During the focus group, participants attempted to collaborate on ways of speaking about disability. This led to moments of agreement and disagreement evidence through their dialogue.

Katy: it was a couple of years ago. They had a big thing when they wanted to get rid of (in a whisper) the word *retarded*.

Alex: I remember that one

Katy: they wanted to get rid of it and now they’re called individuals.

Ann: Consumers, clients, individuals

Katy: They stopped consumers too. And the sad thing about it, to me, is that some of them will tell you, you know (in a whisper) I’m *retarded*.
Danielle: Yeah

Katy: I don’t like to hear that. That word is harsh. It’s like calling someone fat. Like to me it goes neck and neck. I don’t, it’s a harsh word to say cause that’s not who they are. They’re not you’re Sam, you’re Robert. (lower tone of voice) You’re not retarded like you know. Cause some of them they do have a disability but these guys are very smart. And you’ll be shocked, like they are very smart. You have, oh yeah OK, but that R word. I remember it was a big campaign thing going on but some people use it still.

Ann: a lot of people use it, some of them use it

Danielle: I think that people don’t really think of the definition of the word itself. It has a negative connotation on it but it means what does it mean to stop something, like you retard a fire. It’s a real word. It means stop, like to cease or slow down.

Katy: I never knew that

Alex: like you retarded stuff

Danielle: right

Katy: are you serious?

Danielle: but because of…

Susan: cause their growth has basically stopped

Alex: oh good point good point, you need to repeat that (laughter) I don’t know if she got that (laughter)

Danielle: cause whatever other word they chose to replace it with, and probably 10 or 20 years from now, look how many times they’ve changed the word. It’s always going to be
something negative, like oh I’m not a consumer don’t call me that (others: oh yeah) it’s always going to become something else

Ann: I’m not a client

Danielle: I’m not a client, oh and they are going to sound funny when they say I’m not an individual (laughter) I think maybe they might have found the right word this time but who knows because of society. The way they make these people sound and look it’s like (said in a louder tone of voice) oh you are one of them, that’s bad so you’re retarded.

In their discussion of words used to describe developmentally disabled people, they proposed, argued, and countered several different possibilities. The word retarded, in particular, was whispered by two participants like a word that was prohibited. Retarded was also referred to as the r-word. Participants tried to make sense of this word by discussing its definition and why it is applied to developmentally disabled people.

During this exchange, participants also mentioned several other words used to describe developmentally disabled people in the service delivery system, such as: consumer, client, and more recently individual. They discussed the effects that words have on the people and how they apply them in everyday practices. Danielle, however, disagreed with the relevance of the evolution of words since no matter what label is used, it will still be derogatory since it is used to exclude a particular group of people.

Also during their discussion, participants used words that can be considered euphemistic for practices that are restrictive. These words too seemed relevant to the everyday practice of service delivery.
Moderator: and what do you think these words do? Like using a word like portion control? Or you used behavior guidelines

Alex: it justifies us kind of putting them on clamps. It’s just a justification word pretty much for being able to control these guys. It’s really what it is.

Ann: we don’t use control, it’s not control

Alex: it’s trying to make it sound good

Ann: it’s not control. What’s the word they replaced control with? Uhm what is the word, it’s not control…support, it’s support, it’s supporting them

Danielle: but I think that, I honestly don’t have a problem with portion control because if I could follow the diet that they have I probably would be a lot slimmer. And I mean choice. I have a choice which is why I’m not slim.

Similarly, to the discussion on labels, euphemisms relevant to service delivery were seen as changing and evolving in terminology but not in actual practice. The approach to behavior modification went from a practice of behavior control to providing behavioral supports. In their discussion, it is more of a matter of semantics than it is an actual difference in practice. Together they agreed that some terminology is used to disguise restrictions as necessary.

Another instance of agreement and disagreement among participants was their discussion on finding a cure. One participant, Danielle, advocated for a cure. The discussion began with Ann’s assertion that everyone is different and those differences should be accepted.

Ann: I think everybody is different. Somebody’s gotta work with Ron, somebody’s gotta work with Jill. It’s got to be good and bad in the world. We can’t be everybody be the same, we would all be clones.
Danielle: I think they got to find a cure

Ann: you think so?

Moderator: for what?

Danielle: we were talking about curing autism. For someone like the seniors and stuff who have been living with these ailments or whatever you want to call it, their being different. Yeah I said ailment, now what. but like all the people who have been dealing with this stuff for all these years I don’t think that you need to be trying to experiment with different cocktails and all this kind of stuff but as far as understanding them by getting a cure you’ll be able to understand perfect. You’re gonna do research, you’re gonna understand. So the people who still have it and are going to have it forever you’ll be able to understand why they’re doing it and then eventually you’ll lead to the cure so their children won’t have to. Cause if we see all the challenges they have now why would you not want to find a cure.

Alex: We’ll I see the biggest problem with that like said, her family some of them didn’t talk till like 5 years old or something so now think about we’re trying to figure out a cure now one of them 5-year-old, you know her brother who talks normal now, suppose all the cocktails we would have, they would have gave him. Now he’s completely messed up. Because we are so quick to jump to a conclusion and you know they say with people that got sick you know the guy is only going to live for 3 months and those people end up surpassing till like 60 or 70 years cause we hopped to a conclusion. Now suppose we had medication for autism. Can you imagine how many kids who didn’t really have autism we would have gave the medication to. And now they have so many side effects. Kidney
failure all this stuff just because there was one doctor who was so quick to automatically jump the gun and say this guy has autism.

During her argument for a cure, Danielle used the medicalized term *ailment* in defiance of what she expected other participants' reactions would be. She acknowledged that ailment may not be the acceptable term but its usage is inconsequential, “now what?”. From her perspective, a cure would minimize the difficulties and challenges that some disabled people face. It was not so much about enforcing normalization but increasing quality of life. Her argument was countered by other participants and during this exchange she was the sole voice in favor of a cure. After the focus group discussion, Danielle spoke to me individually and expressed that she felt other participants misunderstood her intention. She affirmed that she did not believe that people needed to be changed to conform with normalized standards but that perhaps searching for a cure was a way of keeping developmental disabilities and autism as relevant research topics.

In their discussions, participants’ voices were heard during their individual narratives and then their voices came together in both agreement and disagreement during the focus group. Resolution was not the goal and participants engaged and interacted in a process of collaboration through dialogue. From their words, service delivery for developmentally disabled people was an everyday practice based upon personalized relationships that defied cultural notions of deficiency. Participants demonstrated commitment to their work because of the people they work with.
CHAPTER 5

DISCUSSION

The findings of this study show the complex nature of disability constructs and discourses as these are enacted by service providers in the human service industry for developmentally disabled people. Their stories tell a process of transformation and development that culminates in the self-representation as staff. Staff was constructed as a category that transcends the expectations of direct support professional and emerges from the situated activities and relationships with the people they work with. Through their discourses, the direct support professional identity emerged as the enforcer of regulations and mandates who works with individuals. Similarly, a distinction can be drawn between an actor and an agent. An actor is “a person who is rule-governed or rule-oriented, whereas an agent refers to a person engaged in the exercise of power in the sense of the ability to bring about effects and to (re)constitute the world” (Ahearn, 2001, p. 113). In this study, the direct support professional emerged as an actor and staff as an agent. The direct support professional was charged with enforcing regulations and implementing plans. Staff, however, also exerted power by assuming the position of “knowing best”. Staff was further constructed relationally to the guys who they work with through reciprocal activities and interactions in situated everyday practice. Participants expressed understandings that they learn from and grow with the people they provide services to. The relationships that emerge while doing their work, break down the role of passive service recipient since the self-representation of staff is reliant upon that relationship with the guys.
Although there is a maintenance of power over the people they work with, the staff occupies a subordinate position to administrators who are labeled the higher-ups. In relation to higher-ups, participants expressed that they no longer felt like active agents that can effect change or exercise agency. The relative positioning and the roles of staff, the guys, and higher-ups are evidenced through the discourses enacted during narratives and focus group discussions. Participants spoke about their inability to effect change in the lives of the people they work with because of limitations imposed by contextual factors that are part of the regulated system of service delivery. Like the people they work with, participants too are unable to effect change despite regulations that are meant to transfer power from the professional to the disabled person.

Person-centered-planning, for instance, was intended to change procedures that privileged the opinions of clinicians and administrators. As O'Brien, O'Brien and Mount (1998) described through person-centered planning “it was clear to us that established procedures for individual program planning muted the voices of people with disabilities, family and friends, and direct service workers and amplified the voices of people who occupied clinical roles. Though representatives of the different disciplines comprising a team might argue, and though there were efforts to get "input" from parents and people with disabilities, individual program plans were dominated by a bureaucratic--professional perspective” (p.481). The language used by participants frames a hierarchy of power in which staff emerged as a disempowered group that wants to advocate and serve as an ally for the people they work with but is unable to effect change against the entrenched institutional hierarchies. As Holburn and Vietze (1998) argued, true person-centered-planning cannot be implemented unless there is “less of a prescribed process and more of a direct way to re-orient power to the person [the service recipient]” (p.486).
Participants did not perceive themselves as active agents in their role as direct support professional because of their inability to effect change when confronted with administrative and pragmatic structural forces and their constraints and limitations.

The way that participants constructed their own self-representation in their roles as direct support professionals and staff was relevant to their descriptions of disability. Participants' words also provided insight to the ways that they defined and made sense of developmental disabilities. During their discussions, they conceptualized disability as a consequence of multiple factors including biological, contextual, and the interaction of the two. Some of the contextualized disabling factors discussed include: social exclusion, infantilizing, policy-practice disconnects, and words and labels that result in the limitation of abilities and autonomy. Biological or personal disposition that situates disability within the person were spoken about relevant to people with disabilities requiring more assistance whereas people who required less assistance were spoken of as disabled by society. In other words, people who were described as high-functioning were portrayed as disabled by societal or contextualized factors but disability was seen as an individual deficit in people who were thought of as low-functioning.

Deficit-based language was observed during the narrative interviews and the focus group discussion but this language was used in different ways. When looking at particular words, challenging as a descriptor was used by more participants in their narratives than during the focus group discussion. During the narrative interviews, four participants used the word challenging a total of twelve times to describe someone they work with. During the focus group, challenging was used twice by one participant who did not use it in her narrative. She once used it to refer to the “challenges they [the people she works with] have” and her second usage
involved describing her job responsibilities as a mental challenge because of all the responsibilities she faces at work. The participants who used the word *challenging* during the narratives did not use it during the focus group. Similarly, to the word *challenging*, expressions relating to *having a behavior* were used nine times during the narratives by five participants. During the focus group the word *behavior* was used fifteen times but six times it was used to refer to behavior plans; therefore, not directly referencing a person's behaviors. Another deficit-based word that was used in different ways during the narrative interviews and focus group discussion was *retarded*. *Retarded* and retardation were used twice by one participant during her narrative and she used it to describe a clinical diagnosis. During the focus group, *retarded* was used a total of thirty times by five participants. When the word was first stated, the participant whispered the word as if it was something that was forbidden. During their discussion, *retarded* was not used derisively or pejoratively, rather it was used as an example of a word that people use offensively. In their view this word does not describe the people they work with. Throughout their narratives and focus group discussion, deficit-based words were used despite the description of a socially situated embedded disablement process.

Findings from the study inform the general research questions posed: How do service providers conceptualize developmental disabilities? What language do service providers use to describe developmentally disabled people they work with? Is the language they use driven by policy, cultural narratives, or personal interpretations of developmental disability? Was meaning constructed through dialogic engagement and collaboration? From their stories, the service providers’ perspectives and discourses on developmental disabilities come to light through moments of agreement and disagreement in their attempts to make sense of the people they work
with and their role in the work that they do. Participants conceptualized developmental disabilities as a complex process of disablement. They described transformations of their view of developmentally disability, as well as, a transformation in their definition of their role. In making sense of developmental disabilities and the people that they work with, participants constructed *the individual* in relation to the Direct Support Professional and in turn constructed *staff* relational to *the guys*. The definition of self and the role they play drive practice. The language and practice of everyday service delivery are rooted in the language of participants who construct themselves as *staff* through active engagement with the *guys* they work with through a reciprocal and mutual relationship. This process of co-construction relates to Stetsenko and Arievitch’s (1997) activity theory articulation in that the process by which a person is shaped, recursively shapes the social context through agentic activity.

Participants in this study attempted to exercise agency and they also attempted to teach the people they work with how to engage in agentic activity. Through their activities some participants encouraged agency and this was demonstrated in Ann's description of Clark's story. In her narrative Ann described how she encouraged Clark to advocate for himself, she stated: “you gotta speak up for yourself when they tell you you gonna eat this you say you know do I have a choice”. Ann's account not only describes this man's process from dependence to independence, it also asserts her role helping him become an active agent in his life. Ann's activities, such as encouraging him to get a cell phone and travel independently, transferred agency to Clark so that he was effecting change in his own life.

The direct support professional, however, was unable to effect change when confronted by administrators or regulatory mandates. *Staff* attempted to effect change in the lives of their
guys by teaching them to advocate for themselves. The perception that the people they work with are capable of demonstrating agency entailed defying deficit-based definitions and descriptions despite the assumption that staff knew best.

The findings in this study suggest that participants went through a process of transformation in their view of developmentally disabled people and the definition of the own role. Upon initial engagement with disabled people, there was apprehension and even fear. These initial feelings changed through active engagement and situated interaction. Several participants expressed that before working in this field, they had limited exposure to developmentally disabled people and relied on cultural stereotypes. Interaction and familiarity led participants to see the people they work beyond the imposed descriptor, the individuals, of the local language. Their perspective changed as demonstrated by relationship-based definitions that considered disability irrelevant. Participants described learning and growing into the role of staff based upon their relationship with the guys. Willingness to build these relationships disproved their initial deficit-based views and led to expanded understandings, familiarity, comfort, and even nascent solidarity. Yazbeck, McVilly, and Parmenter’s (2004) looked at attitudes towards intellectually disabled people and they found that women, younger, and higher educated people in their study were more likely to demonstrate a more positive attitude. Their findings also suggest that attitudes are contingent upon cultural perceptions and are mitigated by willingness to interact, lack of awareness, and wariness or hostility (Yazbeck, 2004). In this study, participants’ discussions demonstrate that initially there was a lack of awareness and even wariness which came from preconceived definitions of developmentally disabled people as inherently deficient. There was, however, a willingness to interact based upon personal motivation or
obligation due to work responsibilities and as a result there was a transformation in both perception and attitudes towards the people service providers work with. Their new perspectives on developmentally disabled people were seen in their emerging and more nuanced definitions. Importantly, most participants offer definitions that use descriptors that are not related to disability or medical diagnosis. The use of these definitions indicates that disability is no longer the primary identity marker.

Although disability is not the defining quality of the people they work with, participants attempted to make sense of people who they described as wanting independence but were reliant upon services and assistance from service providers. An aspect of service delivery practices this study attempts to understand is the complex dialectics between individual empowerment and dependence on human services. This was evidenced by the discourses used by participants in their negotiation of disabled people as both independent and dependent. Participants were mandated and made their own attempts at providing independence. Independence in this context was treated as a concrete quality that is given or taught to people who were perceived as dependent. However, receiving services became a factor that contributed to perception of people as passive service recipients dependent upon the service provider, even for independence.

Participants negotiated dependence and independence evidenced by their description of independence as something that is given or taught. Participants attempted to promote independence and agency but from their perspective, the people they work with are reliant upon service providers for assistance and guidance to do “what is best for them”. Similarly, Jingree and Finlay's (2008) work looked at the discourses of support staff who work with learning disabled people in the United Kingdom. One of the themes that emerged was a dichotomy of
autonomy versus practicality. These researchers found that support staff attempted to provide autonomy but were often constricted by institutional limitations and practicalities. Similarly, in this study, participants expressed that they were limited by regulations and daily demands in their attempts to provide independence to the people they work with. Independence was spoken about as something that was given by staff and, like Jingree and Finlay's description of empowerment, empowerment becomes disabling when it is viewed as something that is given since it can also be withheld. Independence and empowerment are also limited by the construction of disabled people as needing help whereby restrictions are justified by an emphasis on health and safety.

Participants identification of their role in their service providing work is directly related to their views of the people they work with and discrepancies arose between the assigned role of direct support professional and the self-assigned role of staff. In participants' accounts, their perception of the role of direct support professional included compliance with regulatory mandates and negotiation of institutional limitations in everyday practice. This supports findings by Jenaro, Vega, Flores and Cruz (2013) who argued that in order to improve quality of care and quality of life, service delivery should focus on the person's choices and interests instead of the needs of the program. Although policies and mandates are in place for individualized planning, in practice, however, pragmatics “on the ground” of situated practices and interactions drive services that are based on needs and not necessarily interests or choices. Needs-based service delivery gives power and control to the service provider. The assumption is that the person is incapable and must be safeguarded for his or her own good. The enforcement of practices that overemphasize health and safety were perceived as barriers by participants and served the
purpose of limitation of independence in activities regardless of the person’s individual capability. Thus, overall, service recipients continue to be viewed as dependent upon others.

I pose that the words used to describe and label people are consequential in the positioning of service providers in relation to the people they work with and these terms are used to justify limitations and restrictions. This occurs when disability is seen as an intrinsic deficiency as it promotes a relation between the service provider as expert and the disabled person as a passive recipient without much agency. If a person is perceived as incapable, their thoughts and opinions can be disqualified as the professional opinion is privileged as discussed by Linton (1998). An instance of this disqualification was observed in this study when a participant referred to a disabled person's expressions as *ramblings*. Restrictions are imposed under the guise of the best interest of the person because the service provider is charged with ensuring health and safety yet such imposition creates a self-perpetuating cycle of dependence and passivity.

In this study, participants discuss the charge of health and safety as a primary professional responsibility of direct support professional. The focus on health and safety as primary responsibilities limits the opportunities for disabled people to engage in mundane and ordinary activities because they are viewed as inherently deficient. The protection of the health and safety of the individual becomes the reasoning for power and control. An individualized approach to the determination of safeguards and risk assessment are part of plan development described in the process of person-centered planning. Concern for health and safety as a necessary part of service provision did not seem to be disputed by participants. Rather they disputed restrictive levels of supervision when they were determined in a top-down fashion removed from particulars of
everyday practice. For instance, this refers to the requirement to supervise some people in naturally private spaces such as in the bathroom. Participants also contested the lack of adequate supports when they were required to provide individualized supervision, such as additional direct support professionals in order to comply with mandates and still afford opportunities for people they work with to engage in activities of their choice. This is seen in Alex’s account of working with a person whose plan requires supervision by two direct support professionals. He explained that inadequate staffing levels prevent this person from participating in community-based activities and thus, restricts opportunities to exercise agency and self-determination.

Participants described their desire to promote autonomy and independence but they were limited by several factors. Firstly, some participants saw the person's individual inability to make choices that were best for them as a limitation. This inability required service providers’ assistance in making decisions. However, participants also described how policies and requirements of the prescribed role of direct support professional also contributed to the limitation of choice-making. Antaki, Finlay, and Walton (2007) also found that although staff members in a group home setting tried to facilitate independent choices, they had to conform to institutional limitations and choices were imposed in a top-down manner resulting in staff having to gear the disabled person’s choices towards particular ends. This was alluded to by Ann who felt obligated to change the minds of her guys on particular decisions they made because those decisions did not conform to mandates. Similarly, Lawrence's explained during his narrative how the role of staff sometimes involves guiding people to make the best choice as determined by the staff person's discretion.
Ability or (dis)ability to make decisions is enforced from an administrative level but it is also enacted in everyday interactions and practices “on the ground”. Administratively, disabled people who receive services are assessed by administrators, clinicians, and other professionals. Assessments are used to determine if a person has the capability to provide consent for medications, behavioral interventions, and sexual relations for instance. On an everyday level, staff make decisions such as food choices and recreational activities. From a narrative interview, Katy mentioned how she designates one particular weekday as the soda day because if it were up to the person she works with he would drink a soda every single day. The limitation of one weekly soda assignment is a normative standard that is subjective and contingent upon the particular direct support professional’s opinion.

When the person is unable to make decisions, the service provider is positioned as knowing best and it allows for the observation, study, and classification of people and their behaviors. In this study, participants discussed their analysis and documentation of non-normalized behaviors. As Broberg (2011) described, disabled bodies are objectified under the surveillance of the professional. The direct support professional is required to observe and document when a person has a behavior that is considered maladaptive or challenging.

Conformity to institutional limitations and the prescribed role of direct support professional, however, was in tension with and resisted by participants as they related to the people they work with through a process of becoming staff. Importantly, during this process there was a breakdown in the cultural dichotomies of normal/abnormal, us/them that are part of a dominant discourse in a disablement process that positions disabled people as outsiders. Through the everyday enactment of the role of staff, participants’ narratives evidenced experiences of
solidarity as they found common traits and parallel experiences that defied these dichotomies and situated staff and the people they work with on the same side of these binaries. This was evidenced in participants' accounts of developmentally disabled people during interactions with non-disabled people who are not part of the human service industry, community members. Some of these interactions demonstrated the experience and management of stigma associated with normative perceptions of disability.

Individual characteristics interact with the social context through multiple factors. The experience of stigma and the inability to effect change were disabling factors discussed by participants. Erving Goffman’s (1963) work defined stigma as an identity marker that defies the norm and is based upon stereotyped beliefs. In their role as staff, participants shared what they perceived was the spoiled identity of the people they work with, finding themselves on one side of the out and them sides of these cultural binaries. Interactions with non-disabled people, or community members as identified by participants, were moments when stereotyped views were enacted and participants described the experience of courtesy stigma. They also described their efforts to manage and mitigate the effects of stigmatization through assertions that staff and the guys are part of their own in-group.

Participants also drew parallels as they described the experience of power differentials relevant to administrators and managers in their inability to effect change in the daily lives of the people they work with. As staff they conveyed that they are unable to advocate when mandates are determined administratively but they also make attempts to promote agency. Ann for instance described how she encouraged someone to speak up for himself when he first moved into a residential group home. She also assisted this person with getting a cell phone and learning how
to travel alone. From her account, she saw her role as helping him effect change in his own life. She exerted agency by facilitating agency.

Participants' ways of theorizing disability were evident in the recognition of the contextualized interpretation of disablement. Their descriptions, after working in this field, demonstrated an understanding of disability as a process that is affected by multiple factors and is embedded in a sociocultural context. In their discussions, they portrayed disability as an interactional and dynamic process mitigated by multiple factors. They described social, economic, historical, and political factors in the creation and maintenance of the social category, disability. Thus on the whole, participants demonstrated nuanced and sophisticated knowledge of social dimensions and approaches in their definitions of disability.

Disability as a process that takes place between the person and the context is also described by Saad Nagi's functional limitation paradigm, which distinguishes between four processes in disablement: active pathology, impairment, functional limitation, and disability (Masala & Petretto, 2008). Participants emphasized functional limitation in that the people they work with were unable to enact specific roles or perform expected functions, such as walking and talking (Masala & Petretto, 2008; Pledger, 2003). Further, this model described functional limitation as the reason they were unable to perform socially defined roles. In this study, walking and talking were two traits described by Ann, during the focus group discussion, as indicative of a child was all right regardless of disability. From participants’ descriptions, it can be deduced that disability was an effect of functional limitations within the social context.
Participants' approaches seem to be based on a belief that disability is a contextualized experience that occurs within social, economic, and historical traditions and contexts that are consequential for everyday practice. In their descriptions of interactions with the greater social context, outside the parameters of the immediate service delivery setting, participants observe social exclusion and discrimination from community members who are unfamiliar and are apprehensive with regards to developmentally disabled people. As Kozulin and Gindis (2007) asserted, the acquisition of culture compensates for impairment but from participants' accounts developmentally disabled people are often deprived from full inclusion in their communities and the benefits of socio-cultural experiences. In addition to social exclusion by non-disabled people, community members, participants in this study also observed the disabling effects of infantilizing and the effects of familial interactions that limit development. They described infantilized family interactions or the lack of family involvement as disabling and prohibitive in the expression of capability therefore contributing to disablement.

Within the service delivery system, participants describe policy-practice disconnects that have disabling effects. Regulations adopted by the state governing agency, the Office for People with Developmental Disabilities, requires a person-centered approach in the development of individualized services (“Person-centered planning,” 2014). Pragmatically, as the present study suggests, this process and these plans seemed elusive to participants who emphasized a policy-practice disconnect that affects the provision of contextualized services within the limits of everyday practice. The policy-practice disconnect promotes disablement through enforcement of practices that are not practical within institutional limitations, thereby denying disabled people the opportunity to exert their choices. For instance, Flynn and Lemay (1999) discussed
community participation and inclusion, personal choice, and valued social roles as part of person-centered planning. Limitations such as level of supervision and everyday practicalities become restrictions in aspects of person-centered service delivery, such as community inclusion. Although participants in this study expressed that they agree with the principles of person-centered planning, they at the same time acknowledged that the pragmatics in implementing individualized plans are prohibitive in carrying out within the parameters of everyday activities that are also part of service delivery.

Participants also spoke of the inability to practice person-centered planning with people who were described as low-functioning and unable to communicate through standardized means, due to a perception of an inability to make choices that are best for them. In those instances, staff were described as better able to advocate and decide. As described by O’Brien, O’Brien, and Mount (1997) person-centered planning is particularly relevant to people who are unable to communicate. A circle of support is intended to find the person's capabilities with the assistance of family, friends, and service providers. As Renzaglia et. al. (2003) described the circle of support is relied upon for people who are unable to communicate their wishes. However, in the present study, participants felt that person-centered planning was applicable to people who can communicate effectively. They expressed that person-centered planning was difficult to implement with people who were unable to provide input on service preferences. The person-centered approach, according to participants, fails to provide ways of including all people regardless of disability into the process of service development.

Further, the role of parents in this study emerged as a disabling factor when parents or families infantilized or rejected their developmentally disabled relative. Person-centered
planning calls for collaborative efforts between families, service providers, and the disabled person in service development. The data however suggested that participants were reluctant to work with parents since they saw parental approaches as prohibitive in the enactment of the role of *staff* as well as disabling for the service recipient. One participant described a person he works with as a “grown baby” due to infantilizing by the person's mother. Participants attributed feelings of guilt to parents and interpreted the child-like treatment of their adult offspring as compensation for those feelings. In their discussion, the service providers argued that the image of a perpetual child results in non-normalized behaviors. The role of the social network, the circle of support, in the development of services includes the participation of the person’s family in collaboration with professionals to provide individualized services. In this study, participants see this as a point of contention as in their accounts family can at times contribute or perpetuate disablement through acts of infantilizing or rejection.

Similarly, person-centered planning emerged in the providers’ discourses as encouraging engagement with non-disabled people in shared spaces, the *community*. In participant’s discussions, contact with the *community* was not always amicable and service providers observed social exclusion and discrimination. Participants experienced courtesy stigma effects of the service recipient’s disability. Stories referenced non-disabled people crossing the street when walking past the group home or a mother pulling her children close to her in a store upon seeing a person with Down Syndrome. Participants witnessed the discriminatory practices by non-disabled people but also used these moments to reassert the disabled person the work with as part of their in-group while speaking of non-disabled people as part of an out-group. Non-disabled people were perceived as lacking an understanding of developmental disability. However,
acceptance was also described as a gradual process of familiarity when non-disabled people began to know particular developmentally disabled people. Participants described the changes they observed by some non-disabled people as a process similar to the one they experienced when they initially began working in this field of work.

During the narrative and focus group discussion, one participant mentioned normalization several times with the assumption that one of the direct support professionals’ duties was to comply with and enforce normalization. Despite discussion on acceptance and difference, normalization is based on the idea that the disabled person should change their behavior and gain skills in order to approximate the normative lifestyle and consequently earn a socially valued role (Culham & Nind, 2003). Activities by non-disabled people are imposed as the normative standard and this was evidenced by participants’ references to their own preferences as the norm. Imposing normative standards is consequential in daily practice in the service delivery industry as normalization becomes a justification for the professional imposition of a particular lifestyle. Similarly, in Calhum’s (2003) description of Wolfensberger’s Social Role Valorization (also referred to as normalization), practitioners are charged with helping people with an intellectual disability do ordinary things, in order for them to gain social value and acceptance. In the data of this study, the practice of helping people do ordinary things also related to the actions of giving and teaching independence.

The conceptualization of disability was socially situated is evidenced during the discussion; however, deficit-based discourses were used by participants in this study. Although some participants used medicalized terms and deficit-based discourses, their perceptions and descriptions were based upon contextualized factors. Participants were more likely to use deficit-
based discourses during their individual interviews while describing disabled people than during the focus group. During focus group discussions, participants engaged in dialogue and interactions in attempts to make sense of the words and language that they use. Their views were in conflict at times. During these moments, they monitored what they said by referencing one another and clarifying what they wanted to say. Participants expressed a connection between language, perception, and power as dimensions of situated activities and practices by discussing the effects of words and labels on the experience of disability.

The dominant cultural narrative talks about developmental disability through deficit-based language construed through the lens of medical views. This understanding results in the view of developmentally disabled people as in need of care, dependent upon others, and it internally situates disability. The language of the medical model of disability was part of the discourses observed during this study. Application of the medical model and deficit-based discourses were relevant to people who were perceived as low-functioning or more severely disabled. Although there was an understanding of disability as a complex, socially embedded process that results in the category of disabled, medical and deficit discourses persisted. Similar findings were discussed by Ferri, Connor, Solis, Valle, and Volpitta (2005) who looked at the ways in which four teachers with learning disabilities negotiated disability discourses. Their findings showed that the use of cultural and professional discourses along with the lived experience of learning disability presented both internalization and resistance to dominant discourses. In their work, Stamou and Padelia (2009) interviewed teacher candidates and found that medical discourses accounted for more than half of the discourses used during their study. Teacher candidates were trained on social perspectives on disability but yet in their
discussions they drew upon medical discourses showing that deficit based attitudes continue to make their way into professional discourse. According to Simi Linton (1998) discourses used by professionals include words that are oppressive.

In their discussion on specific words used to describe developmentally disabled people, one particular word that participants debated was *retarded*. One participant referenced a 2007 campaign that emerged online attempting to erase the r-word. When saying this word, some participants used the expression *r-word* indicative of a cultural prohibition in stating the actual word and others whispered the word. This particular word became a point of disagreement with some participants referencing it as a clinical term and not necessarily a derogatory remark. There was agreement among participants that this word is used without necessarily understanding the word's origin or actual meaning. The word is used derisively by non-disabled people and unexpectedly this word was applied to people that they perceived as severely disabled.

Charlton's (2000) discussion on words mentions *handicap, cripple, or invalid*, as words that are no longer part of the professional jargon and this is reflected in this study. These are words that are not used by any of the participants neither during the individual narratives nor during the focus group discussion. Charlton (2000) also mentions words such as *patient, client, population, and consumer* which continue to be used by medical and social service professionals. In this study, one participant expressed a medically inclined perspective more than other participants and this person used the word client and population during her narrative and discussion.
Consumer was a word that participants discussed but did not actually use to refer to the people they work with. It is seen as an older word used to describe the people they work with and it was once the term used by this particular organization they work for. This word has been replaced by individual but participants argue that the new word serves the same function as consumer. Special is another seemingly innocuous word, discussed by Linton (1998), as a euphemism for undesirable people. Special is used by one participant but only when she refers to a disabled family member. She does not use the word to describe disabled people she works with. From her different descriptions, perhaps a distinction can be drawn between the conceptualization of disabled people and disabled people that receive services.

Lastly, normal is another word used by participants in several different ways. In the narratives, normal appears nine times and is used by three participants. Normal was used twenty-seven times during the focus group discussion. Participants, however, did not use normal in a way that devalues the people they work with. Grue (2011) discussed how applying the word normal to people carries a moral judgment in which deviation from average is assigned a value of less worthy. In this study, several participants asserted normalcy and reiterated that the people they work with are normal. The word was used to resist the expectation of non-normalcy. Some participants went further and listed common traits shared by developmentally disabled people and non-disabled people to reaffirm the claim to normalcy. Normal appears to be the standard that indicates similarity, not difference.

Normal, however, was also used to refer to a particular lifestyle that participants felt they were unable to provide for the people they work with. Their discussion on services and practices, that seemed out of touch with everyday practice, led them to discuss normalization and how
these services and practices impede a *normal* life. They described their practice as standing outside of normalcy and used their own lifestyle and preferences as reference. For instance, one participant states that when he comes home from work he does not leave his house for the rest of the day so asking the person he works with to go for a walk after returning home from his day program, to comply with *community inclusion*, is described as outside of normalcy.

During the focus group, most participants argued for the acceptance of differences and conceptualized developmental disability as a difference not a deficiency which is congruent with neurodiversity. All participants expressed lack of familiarity with the term neurodiversity although they expressed agreement with some of its principles without actually knowing the term. Unfamiliarity with neurodiversity was expected given that previous research by Kapp et al. (2012) found that autistic people and their friends were most likely to have knowledge of neurodiversity while relatives and people with no relation to autism were unfamiliar with neurodiversity. Unfamiliarity with neurodiversity was also expected since it is not part of the current discourse in disability services.

Although participants demonstrated unfamiliarity with the term neurodiversity, their discussions were at an intersection between biological and socially based understandings of disability. As illustrated in table 7, in comparison to neurodiversity and sociocultural or constructivists perspectives participants described disability as distributed between social and individual factors. Most participants spoke of disability as difference, similarly to the neurodiversity perspective. From a sociocultural perspective, disability occurs in the interaction between the person and social context. Although participants recognized socially contextualized interactions as disabling, their views more closely resembled those of social models of disability.
with a focus on social, structural, and attitudinal barriers. Through situated practices, participants distribute disability to both internal and external factors.

The local language enacted by participants was practice-based and combined their own words and those of the regulatory system. The language of neurodiversity emphasizes neurological difference as a naturally occurring fact, part of human variation. Although all people demonstrate strengths and weaknesses, neurodivergent people experience difficulties because of lack of accommodations, accommodations that would improve quality of life. The neurodiversity movement wants acceptance of differences and diversity valued. The sociocultural approach focuses on interaction and scaffolding. Interaction is the unit-of-analysis and it is socially situated. Teaching and learning occur through collaboration and the goal of pedagogy is to diminish the effects of disability through the acquisition of cultural tools and higher psychological functions. Participants’ experiences with disability were primarily practice-based and they attempted to negotiate institutional limitations and a sense of agency. Service provision was at times in tension with their attempts to promote independence and autonomy.
Table 7
Contrast of neurodiversity, sociocultural and situated practice

<table>
<thead>
<tr>
<th></th>
<th>Neurodiversity Approach</th>
<th>Sociocultural theory</th>
<th>Situated practice perspective</th>
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| **Where is disability?** | Difference not disorder  
Biologically-based way of being | Interaction between person and context | Disability is situated and distributed internally and externally |
| **Key terms and language** | Neurologically-Diverse  
Human variation  
Neurotypical | Interaction  
Participation  
Mediation | Individuals/Guys  
Staff  
Community members  
Restrictions/Policies |
| **Context** | Lack of accommodations creates challenges  
Quality of life  
Autistic culture | Person-in-activity  
Collaboration  
Socially situated | Practice-based  
Tension between institutional limitations/regulations and agency |
| **Stress on** | Acceptance  
Individuality  
Right to be different  
Diversity is valuable  
Respect | Pedagogy, scaffolding, development  
Higher psychological functions  
Value of knowledge and mastery  
Cultural tools | Services, support, care, solidarity  
Tension between provision of services and independence/autonomy |

Through their local lexicon of disability, participants' words go beyond the language of policies, cultural narratives, and personal interpretations. Words are claimed and redefined to fit into everyday situated practices. *Individuals* become *guys*, normal is used to validate, and *retarded* is unspoken. In becoming *staff*, participants move past the direct support professional identity as the enforcer of policies and restrictions and instead, embrace the role of *staff* who acts...
as family who knows best the people they work with and can be of assistance to them. In their discussion there are social voices from a cultural narrative and voices of a local dialect that position disabled people as dependent but participants also reconstruct the individual and themselves relationally. As Asaba and Jackson (2011) describe Bakhtin’s notion of heteroglossia and Holland’s Dialogic self, in order to explain how social voices, become part of the self, this process of self-authorship does not occur within the individual outside of the social context. The self is constructed from practices and discourses and internal voices are based upon collective discourses. As the cultural narrative constructs developmentally disabled people as dependent and in need of care, participants enact this view in practice and in the self-representation of their role as caretakers and guardians who promote independence but ultimately know what is best for the person.

Through their narratives and discussions, participants made sense of the people they work with in close relationship with making sense of their role in the work that they do. Using both narratives and focus group discussion gave the opportunity to hear the voices within and between participants. Bakhtin’s theories on internal and external dialogism guided the use of narrative inquiry and focus group method in order to explore participants’ individual perspectives and their ideas in interaction. Internal dialogue does not occur in isolation as it is situated in a socio-historical context. The narratives gave insight into their internal dialogue and their individual opinions and discourses. Through dialogic interaction participants collaborated on ways of speaking of disability and their role in the human service industry. The process of understanding disability occurred through dialogic and multivocal interaction not by the researcher deliberately teaching an alternative approach. During the focus group, the addressivity of an utterance was
seen in moments of disagreement when participants looked towards each other for responses in attempts to make meaning. Moments of heteroglossia, when multiple voices came together in a dialogue in both agreement and in tension to create polyphony, and resulted in interactions that did not necessarily have an end point or resolution (Nikulin, 1998). Moments of polyphony were evident during participants’ discussion on finding a cure. Participants also agreed and disagreed on terminology and approaches to disability without resolution on either topic.

During moments of agreement and disagreement, I attempted to collaborate with participants during their discussion without imposing my viewpoint. In keeping with Stetsenko’s (2010) notion of collaborative purposeful transformation, through which teaching-learning and development occur in a process in which the learner is an active contributor to the creation of shared knowledge and to individual identity by engaging the social environment, I attempted to collaborate but also moderate so participants engaged one another in their understanding of disability and human services. Through engagement and shared experiences, their individual thoughts became part of a collective voice and growing awareness. Unexpectedly, in this study, the direct support professional self-identified as a disadvantaged, disempowered group that felt powerless and voiceless. Focus groups research has become relevant to action research with disadvantaged social groups and has been used as a conscious-raising tool to foster social change, as in Friere’s “dialogic method” (Wilkinson, 1999). Participants expressed that participating in the focus group gave them an opportunity to have their voices heard.

The findings of this study showed that service providers can embrace a worldview that does not situate disability within the individual or speak of it as a personal deficiency. Participants demonstrated awareness of discourses and their effects when they advocated for and
argued about different terms and ways of conceptualizing disability. As Bamberg (2004) proposes, people exercise agency in creating counter-discourses. Participants' attempts to make sense of and negotiate their understanding of developmental disability and the people they work with can be seen in their representations and ways of speaking.

**Limitations**

The data from this study provided insight to the ways that participants define disability and the discourses they enact in service delivery but these findings cannot be generalized to direct support professionals in general. Due to the small number of participants and the homogeneity of the group, the results represent these particular participants. The small number of participants in this study was intentional in order to facilitate discussion during the focus group.

There was a difference in the number of participants that completed the interview and attended the focus group discussion. Two participants completed the individual interview but did not attend the focus group. The two participants that did not attend the focus group were Mary and Lawrence. Lawrence had greatest number of years of experience in this field of work and Mary had ten years of experience. During the individual interviews, the Mary seemed to struggle providing answers to the questions and referenced me for confirmation that her answers were within my expectation. Mary’s also provided the shortest interview. Lawrence, on the other hand, provided the longest individual interview and presented several of his own ideas outside of the research questions I posed.

A common aspect among participants was that recruitment for participation was limited to one non-profit organization. Organizations have different approaches, policies, and training
procedures which create micro-cultures. Service providers develop ways of speaking, a local language, and ways of implementing plans and services that become specific to the organization’s procedure in service delivery. In this study this was evidenced in the language used by participants and the changes they observed such as a time when they referred to people as *clients*, then *consumers*, and now *individuals*.

Questions on demographic information also revealed several common traits among participants. Seven of the nine participants were female, and seven participants self-identified as black or African-American. The highest educational degree earned was an associate’s degree with seven of the nine participants having some college level experience. Experience in this field of work appears to be relevant to participation in this research study as the average number of years of work experience was ten. The least experienced person had been working for two years and the most experienced had over thirty years of experience. Direct support professionals with years of experience may have different ways of thinking about the work that they do and the people they work with. Results may have been different with new employees. Extensive work experience may also account for interest in research participation as the participants are apparently vested in the work that they do. Since recruitment for participation was based upon self-selection, more experienced employees may have chosen to participate in research relevant to their work compared to less experienced employees.

This study was limited to the viewpoints and discourses of direct support professionals. Although research interests in professional disability discourses was the result of my earlier study with self-advocates, disabled people were not part of this research study. Additionally,
other groups within the field of human services were excluded from participation, such as administrators and clinicians.

A limitation in the methods relates to the web-based reading excerpts referenced during the focus group. Participants seemed more interested in discussing topics that related to their daily experiences. They seemed less responsive to excerpts that presented theoretical perspectives. Readings that were applicable to daily work were referenced whereas the more theoretically based works were not discussed. One topic of conversation involved the use of the word passion over the word obsession when describing the interests of an autistic girl. Participants used this instance to show how the words used in treatment and behavior plans influence their thought processes regarding the people they work with.

Participants also seemed reluctant to discuss topics that sounded unfamiliar. Despite my attempts to introduce neurodiversity as a topic of conversation, participants focused on a more practice-based, situated understanding. Participants relayed their own personal experiences in the work that they do. Although they discussed the relevance of words and how words influence perceptions, participants did not engage with the language of neurodiversity but relied on deficit-based discourses and the local language of their organization.

**Implications for Practice, Policy and Future Research**

From participants’ accounts, language and discourses used in treatment plans and policies are influential in everyday practice. The discourses enacted through policies and regulations have direct consequences for the perceptions of disability and have the effect of situating disability either within the person or within a sociocultural realm that cannot be reduced to personal
deficits. From participants’ discussions, it emerges that policies are directly influential in impacting the daily practice by effecting change in the ways that disabled people are defined and acted upon.

Participants also demonstrated awareness of their own discourses when they engaged one another during the focus group. At different points in discussion, participants socially referenced one another when using particular words. This study also suggests that awareness of language and discourses influences the perceptions participants have of the people they work with.

Beyond the language of policies, however, the disconnect between policy and practice translates into a barrier in everyday service delivery as policies are seen as out of touch with daily life. This suggests that policies may interfere with everyday practice since they are not based on the direct experiences of contextualized service delivery. This was particularly evident in this study's findings of how the service providers perceived the requirement of parental involvement and mandates to include families in the development of services. Participants perceived particular parental interactions as disabling. Policies such as person-centered planning mandate inclusion of family but participants in this study viewed family members as part of a disabling process enacted through either acts of infantilizing or rejection of their disabled family members. They described these actions as undermining the efforts of staff members in promoting independence and adaptive behaviors. In order to further policies in this area, research is needed on approaches that would position family, service providers, and administrators, as allies but uphold the disabled person as the driving force in service development.
In light of the limitations and implications of this study, it can be suggested that future research should involve administrators, parents, and disabled people. They may offer different views and ways of speaking of disability that may contribute to this field of research. The perceptions and discourses of disabled people who receive services as well as disabled people who do not receive support services may reveal differences and further advance research and understandings of the complexities involved in discourses and practices related to the construal of disability. Also, field studies may be a useful method in understanding discourses in their naturally occurring contexts and practices. Research in other service providing organizations may also reveal different results as the language and approach may be specific to each particular organization and practice field.

Relating to the research methods, the use of multiple focus group sessions using the same participants may be an effective tool in the process of collaboration to give participants an opportunity to engage in dialogue after initial contact and interaction. Multiple focus group sessions can foster relationships, increase comfort levels among participants that may in turn impact conversations and interactions.

Future research is needed to provide insight into how the discourses and language of disability are enacted in the daily practices and experiences of service providers as an important context in which these discourses and language come to be realized and enacted in complex and often contested ways. From the present study, the narratives and dialogues by participants revealed that words are enmeshed with perceptions, experiences and practices which in turn influence how the work of service delivery is conducted. Language in policies and plans translate into everyday practices that can create a narrative that disables or one that enables.
Conclusion

With the purpose of exploring discourses and ways of theorizing disability, this study attempted to promote awareness of neurodiversity and disablement as alternatives to deficit-based, medicalized perspectives. The findings of this study inform the different perceptions of disability through varying discourses enacted by direct support professionals. Results address the general research questions posed but some findings were unexpected.

The results suggest that service providers came into this research study with an understanding of developmental disabilities is a socially contextualized experience. They attributed disablement to socially-embedded experiences such as interactions with family members, non-disabled people, and even life within the parameters of the service industry. Disability was seen as occurring in the social context of situated practices and interactions but severely disabled people were conceptualized as intrinsically disabled. Most participants came into this study with a socially contextualized understanding of disability prior to introduction to non-deficit based approaches. With the exception of one participant who demonstrated a medicalized approach and used deficit-based language to define disabled people throughout both phases of data collection, participants generally described disabilities as naturally occurring differences, not necessarily deficits.

Disability as a socially constructed category was also identified by participants. They agreed that disabled people represent a marginalized group because of social forces, similar to the experiences of racial minorities. Finding commonality between the social experience of disability and racial minority status is particularly relevant in this study. All participants self-
identified as either African-American/black or Latino/Hispanic and participants were also aware of my identification as a racial minority. There was a shared awareness that categories such as racial groups and disability are social constructs that are used define and delimit people. There was also a collective understanding of the effects of racial minority status when confronted with social barriers and exclusion. This common experience can present the opportunity for direct support professionals to act as political allies in the disability rights movement, not just as guardians or caretakers in their role as service providers. The recognition of disabled people as a socially oppressed is furthered by the idea that socially oppressive attitudes and barriers create and maintain disability.

The ways that participants theorized disability was at times incongruent with the different ways of speaking. Deficit-based language was used differently during narrative interviews and the focus group discussion. This was an indication that participants recognize the negative social consequences of using deficit-based language and attempted to appear more socially aware to create a more favorable impression in the presence of other participants. During the narratives, deficit-based words were used to describe the people they work with. During the focus group, however, certain words were whispered and participants looked to one another to assess if it was acceptable to use particular terms. Certain words were also pronounced and enunciated in an exaggerated manner to emphasize their pejorative nature. Remarkable, participants collectively enacted different discourses than they did individually.

The discourses enacted by participants suggest language continues to emerge and be in transition. The language and concepts on disability that participants used initially were driven by cultural narratives that posit disability as a deficit and disabled people as an outside group to be
treated with trepidation. Concepts on developmental disability shifted from culturally-based understandings to local/organization-based to a personalized, relational approach that was based on relationships. Participants moved from using words and concepts that they knew before they worked in this field. Their language incorporated official words and local language, an institutional language, based upon the words of the service delivery system. This local language included terms like *the individual*, *direct support professional*, and service-driven terms such as *community inclusion*. Participants also enacted situated, practice-based discourses that emerged “on the ground”. This language included personalized expressions such as *the guys*. Along with this change, participants represented themselves as *staff* instead of direct support professionals. The ways that they spoke about disabled people and themselves is relevant to the ways that they conceptualized disability.

An unexpected finding of this study was participants’ perception of themselves as disempowered and unable to effect change with administrators. Participants attributed their lack of agency to the inability to effect change in the lives of the people they work with and in their position as employees. Participants, however, did effect change in the lives of the people they work with. Their perception may be a result of feeling as if they lack agency when confronted by administrative power. Participants expressed that participation in the focus group gave them an opportunity to speak freely and felt empowered through sharing common experiences with other participants. They requested future focus group sessions and one participant suggested similar meetings with administrators in order to understand their perspectives.

Another unexpected finding was the perceived contention between direct support professional, administrators, and families. Instead of working in collaboration as mandated by
person-centered planning, participants described conflicting views between direct support professional, administrators, and families. The disunion excludes the voices of disabled people as each group asserts knowing the person best. From a past marred by institutionalization to a present that still struggles with giving disabled people a voice, the service industry can be a system that effects positive change through collaboration.

As a researcher, parent, and professional within the human service industry I find myself in an intersection of three self-identifications that have the potential to effect change in the lives of disabled people. From this position I am afforded a perspective that understands the purpose of mandates but resists the enforcement of disempowerment. This position provides a multifaceted perspective but it also provides the opportunity to effect change. This study has taught me that common purpose can be achieved through collaboration.

From this study, I have also learned the complexities of language when speaking of disability. As participants negotiated different ways of speaking, I have negotiated ways of writing and found discomfort with particular words. For instance, the juxtaposition of the service provider is the designated service recipient but recipient connotes passivity. It has been difficult to find words that are not disabling and that contest deficit-based language. Although conceptualizations of disability have evolved, language appears to be at a transition point in which discourses are still emerging. Understanding that if the ways we speak and think of concepts are co-constructive, the conclusion is that disability terms are best determined by disabled people themselves. A true union of disabled people, parents, professionals, and support staff can truly effect change not just in the lives of disabled people but in public perception and cultural narrative. From this study, I have come to understand that what matters most is not
necessarily the words or terms used but the concepts that drive them, the practices in which they are enacted, and the effects those words have. The lexicon of deficiency can be replaced with a lexicon of acceptance and solidarity.
Appendices

Appendix A: Interview Questions

How would describe the people you work with?
Tell me about a person whose story you would like to share.
What is the person’s life like?
What do you see as your role when you work with this person?
What do you think about person-centered-planning?
What are your thoughts on people’s abilities to make choices and decide for themselves?
Are you familiar with the ideas of neurodiversity or the process of disablement?

Appendix B: Focus Group Questions

Do you think that the people you work with are very different from other people?
Think about how they may be different or how they may be similar to other people?
What is your opinion on the words used to describe the people you work with?
What are some things that can affect (or influence) a person’s life?
What are your thoughts on the readings?
What are your thoughts on the relevance of neurodiversity and disablement to your everyday work?
Appendix C: Demographic Information

Demographic information:

1. Program/work setting:
   a. Adult Day Program
   b. Adult Residential
   c. Adult Recreational/Respite
   d. Other _____________________

2. Years of work experience in the field of developmental disabilities services: _______

3. Level of Education:
   a. High School/GED
   b. Some College
   c. Associate’s Degree
   d. Bachelor’s Degree
   e. Graduate Degree

4. Gender Identification: ___________

5. Racial Identification: ___________
Appendix D: Consent Form

Consent to Participate in Research

My name is Enitza Carril and I am a doctoral candidate in the Developmental Psychology Ph.D. Program at The Graduate Center of the City University of New York (CUNY). I am conducting a research study on the thoughts and opinions on developmental disabilities by people who work in the human service industry. I would like to hear about your opinions from your perspective.

I would like to conduct an individual interview with you and a group discussion with you and other participants. The individual interview will last approximately 45 minutes and the group discussion will last approximately 90 minutes. I would like to audio record the interview and discussion so I can collect the details accurately. Within legal and ethical boundaries, we will maintain the confidentiality of all information obtained. All written information will be kept in a locked cabinet and electronic files will be protected with passwords. This study may be published but names of people, or any identifying characteristics, will not be used in any of the publications.

There is no known risk or discomfort as a result of participating in this research other than what you might encounter in daily life. It is possible that a participant may experience fatigue or negative emotions during discussion. Participation in this study is completely voluntary and you can refuse to answer any questions or end participation at any time. There may not be direct benefits for a participant. However, an opportunity to discuss one’s thoughts and opinions can be positive for some people. There will be a maximum of 10 participants taking part in this study.
If you would like a copy of the study, please provide me with your address and I will send you a copy in the future.

If you have any questions about this research, you can contact me at 917-667-2172, ecarril@gc.cuny.edu, or my advisor Dr. Anna Stetsenko at 212-817-8715, astetsenko@gc.cuny.edu. If you have questions about your rights as a research participant, or you have comments or concerns that you would like to discuss with someone other than the researchers, please call the CUNY Research Compliance Administrator at 646-664-8918. Alternately, you can write to: CUNY Office of the Vice Chancellor for Research, Attn: Research Compliance Administrator, 205 East 42nd Street, New York, NY 10017.

Thank you for your participation in the study. You will receive a copy of this consent form to keep.

**Consent to research participation**

*I have read the consent form on the opposite side of this page and have had all of my questions answered to my satisfaction.*

I, ____________________________, agree to participate in this research.

*(print name)*

*I agree to have my interview and discussion audio recorded:*  
Yes ☐ No ☐

_________________________  __________________________  
Participant’s signature   Date

*I have fully explained the above including any risks or benefits, and believe the participant understands the nature and purposes of the study with sufficient capacity to consent. I also have offered to answer any questions relating to the study and have fully and completely answered all such questions.*

_________________________  __________________________  
Signature of Person Obtaining Consent   Date
Appendix E: Advertisement Flier

Research Participants Needed

A doctoral candidate from CUNY’s Graduate Center is interested in interviewing staff members in the field of developmental disabilities services. I want to hear your thoughts and opinions.

Eligibility: 1. Work directly with developmentally disabled people

2. Willing to express thoughts and opinions by participating in:

   A. One individual interview (less than 1 hour)

   B. One focus group discussion with the researcher and other participants (less than 2 hours)

Please email or call if you are interested or would like more information.

(Contact information)
Appendix F: Focus Group Reading References

Website: http://www.autreat.com/dont_mourn.html

Excerpt: Don’t Mourn for Us by Jim Sinclair

I invite you to look at our autism, and look at your grief, from our perspective:

Autism is not an appendage: Autism isn't something a person has, or a "shell" that a person is trapped inside. There's no normal child hidden behind the autism. Autism is a way of being. It is pervasive; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person--and if it were possible, the person you'd have left would not be the same person you started with.

This is important, so take a moment to consider it: Autism is a way of being. It is not possible to separate the person from the autism.

Autism is not an impenetrable wall: It takes more work to communicate with someone whose native language isn't the same as yours. And autism goes deeper than language and culture; autistic people are "foreigners" in any society. You're going to have to give up your assumptions about shared meanings. You're going to have to learn to back up to levels more basic than you've probably thought about before, to translate, and to check to make sure your translations are understood. You're going to have to give up the certainty that comes of being on your own familiar territory, of knowing you're in charge, and let your child teach you a little of her language, guide you a little way into his world.

Website: http://autisticadvocacy.org/2012/05/autism-being-autistic-and-acceptance/

Excerpt: Autism, Being Autistic and Acceptance by Amy Sequenzia

What is our place in the world? Who are we?
Those questions should be easy to answer. Yet, they are not.

For a long time, and still today, the answer to the “who are we” question was not directed at us. Non-autistic people defined autism and autistic for us. We were told who we are, why we are “like this” and what we should do to “get better”.

Some of us, deemed hopeless, were told that the only place for us was an institution. But we were not really told anything. Nobody talked to us. Our parents were given the “sad news” and shown the bleak future ahead, the “lost lives” of their children. We were sent to isolated Special Schools, segregated classrooms, we were thought to be unable to learn or to relate to others, given therapies to make us look and act “more normal”.

Neurodiversity wasn’t yet a word. Autistic people were a mystery, our lives without a future. Some autistics, after intense “training” on how, for example, stop stimming, would become poster children for the therapies that “modified” their behavior. Such therapies ignored the real reasons for stimming and made the neurotypicals around those autistics more comfortable.

Some things like making eye contact with any and everyone was thought to be vital to prove that we could understand human relationships; flapping hands or spinning were labeled annoyance and non-compliance; covering our ears, rocking, and avoiding being touched, despite being understood as being sensory related, were still something to be modified, stopped.

The neurotypical community did not know how to include us; they did not know how to approach us; worse, they didn’t really want to interact with us. So they boxed us, transformed us into puzzle pieces and called us “a mystery”. That may sound better than words and definitions that hurt like “retarded”, “weird”, “severe”, and expressions like “not capable of human empathy”, “not able to feel emotions”. But being labeled a mystery is not a good thing either. I
know who I am and I am not mysterious. If I accept this concept, I will be denying who I am, I would accept that someone should uncover the “real” me.

So, who are we and why do we want acceptance?

We are part of a spectrum and we are unique individuals. In this sense, we are not different from neurotypicals. Everyone is unique. What’s different about us is how we react to, and interact with, external factors and how we process and perceive them. We might also have a different way of communicating. Some of us might have difficulties expressing our thoughts or we might need extra time to arrange them in our heads before speaking; some of us don’t speak at all. Non-speaking autistics are not “non-understanding” autistics.

Being autistic is not “hard” or a reason for pity. We don’t know how not to be autistic, happiness and accomplishments are not impossible goals. The problem arises when non-autistics perceive us as damaged people, as people who should be sheltered and isolated, cut away from life experiences; when we are said to be too difficult to be part of a more diverse community; or when families become the focus of all the “hardships that an autistic child brings”. Sometimes autistics that are less disabled – or look less disabled – are called weird, self-centered. Their accomplishments not fully valued and their hidden disabilities not taken into account.

So, the neurotypical world became fully aware of us, of our different ways. But it was, and still is in many senses, very patronizing. For the reasons I already described – the focus on the families’ “suffering”, the behavior therapies that would “make us better”, the almost complete exclusion of autistics from the conversation – the awareness never really moved too far.

I don’t say that with contempt or lack of gratitude. Many of the people who were my allies in many phases of my life worked tirelessly and did their best with the information, knowledge and
resources they had at the time. Some of them are allies in the neurodiversity movement today. I believe my experience is not unique.

To answer the question “what is our place in the world”, I need to talk about acceptance. We do not have a place in the world if the world does not recognize us for who we are, the way we are. Acceptance means working with us, autistics, to find ways for us to better succeed. Acceptance means listening to us on the matters that affect us, and respecting our inputs. Acceptance means recognizing that autism is a big spectrum and that labels like “low functioning” segregates ideas and that everyone has something to say; and that labels like “high functioning” does not make those autistics immune from very real issues that need accommodations.

Acceptance will make awareness practical, real. It will bring neurodiversity to the everyday lives of differently able people. Autistics will have the louder voice on matters concerning autism. This will make it possible for us to have the same opportunities as everyone else.

None of this will be possible without collaboration from parents, teachers and other allies that have already embraced neurodiversity.

Website: http://disabilitystudies.nl/sites/20151212.disabilitystudies.nl/files/beeld/onderwijs/reading_rosie_pdf.pdf

Excerpt: Dan Goodley & Katherine Runswick-Cole

(i) Rosie has autism – a reading from the autism canon. Despite autism affecting three times as many boys as girls (NAS, n.d.), Rosie has a diagnosis of autism. Her condition was identified when she was three as a result of her parents’ concern about her significant language delay and lack of social skills. Ripples of the condition are often found in families with children with
autism, with non-autistic relatives often displaying autistic traits (Piven et al., 1997). It is not, therefore, surprising that Rosie’s older brother is studying natural science at university. The data demonstrate that Rosie suffers from many of the characteristics typical of an autistic child. Rosie is object-focused rather than people-focused. Rosie took a photo of her mother, father and the researcher, but the primary focus of these pictures was her new toy, Kitty, that is her latest obsession. This object focus is typical for autistic children. As she took the photos, Rosie also demonstrated an obsessive preoccupation with patterning as she organized the shots in a systematic way, demonstrating her tendency to perfectionism (Attwood, 2007). Encouragingly for her future development, Rosie has more than one special interest. As well as obsessing about Kitty, her new toy, she also shows an obsessive interest in Goodies DVDs and Greek myths. Rosie has an impressive knowledge of vocabulary on the topic of Greek myths, however, this seemingly developed area of competence is a product of her fascination with mythology and should not distract from an understanding of the devastating impact of autism and learning difficulty on her life. However, it is useful to continue to channel Rosie’s obsessive interests positively in terms of her education with the aim of widening her vocabulary. Rosie is educated in a special school, as she would clearly be unable to function in a normal mainstream school. Unusually, Rosie’s father noted, unlike many autistic children Rosie does not enjoy Thomas the Tank Engine DVDs. Typically for an autistic child, Rosie has an impressive memory (Attwood, 2007). Rosie was able to recite the plot lines of her favorite DVDs in great detail. However, she struggles with team situations (ibid.) and is very self-directed, following her own agenda. Once she had tired of the activity of taking photographs, it was not possible to re-engage her attention. Rosie communicates in a typically autistic monotone that varied little throughout the research.
encounter. As the research encounters took place in her own home, Rosie was familiar with the sensory stimuli around her, although she did struggle when the sun moved round onto her face. Rosie’s photographs offer a fascinating insight into the autistic mind and allow us to enter her world, albeit briefly.

(ii) Rosie is disabled – a reading from social model orthodoxy. Rosie lives in an area of social deprivation in a town in the north-west of England. Rosie’s father works, but, typically for mothers of disabled children, Rosie’s mother has been forced to reduce her part-time work because of difficulties in finding appropriate and affordable childcare for Rosie (EDCM, 2007). All of the research encounters took place in the home. This is not surprising. For many families living with disabled children, simply leaving the house requires the family to overcome a significant number of barriers. First, there are often access issues in terms of negotiating doorsteps, accessing public transport and finding physically accessible locations to visit. However, for Rosie’s family it is attitudinal barriers that mean that they are confronted by ‘tuts’ and stares as Rosie behaves ‘differently’ outside the home (Ryan, 2005). Disabling attitudes mean that Rosie is marginalized in her local community and subject to the processes of exclusion. Rosie attends special school, revealing the failure of schools to implement the principles of inclusive education (CSIE, n.d.). Rosie’s attendance at special school also reflects an inability on the part of her parents to see that their children could be included in mainstream education (BCODP, 2005). While parents can and do act as allies to their disabled children, they are also the ‘agents of disabilism’ (Thomas, 1999) and this is also evidenced by Rosie’s parents’ removing her from mainstream leisure activities and, instead, accessing segregated leisure activities for children with her particular impairment. Rosie’s story demonstrates the continued
presence of the persistent material, structural and attitudinal barriers to the inclusion of disabled people and the continued pressing need for barrier removal.

(iii) Rosie has a world around her – a Nordic relational model reading. Rosie is autistic. Rosie’s story reveals a happy, playful child interacting with her parents and the researcher in her own home. Rosie’s parents and the researcher are attentive to Rosie, allowing her to take charge of the camera and set her own agenda in choosing what is to be photographed and how. Rosie is comfortable in her home environment, supported by her parents. However, when other children visit the home, the environment because busy and confusing – there is a person/environment mismatch that causes Rosie difficulty. Rosie would prefer to be in a less busy environment with people in it who support her. Rosie loves going to the theatre and watching her favorite shows and characters. This is an environment in which Rosie thrives. Rosie enjoys school. She is encouraged to enjoy her passion for Greek myths and to enjoy the activities there, including learning to play the flute. Rosie and her parents feel the school environment meets her needs.

Caring and enabling professional experts support Rosie’s inclusion in the special school environment. In terms of normalization, the family is able to access many of the regular activities of the wider society, going to the theatre or the park, but Rosie needs support in these environments in order to ensure that they are accessible for her. ‘Tuts’ and stares suggest that Rosie’s behavior, status and appearance are not culturally ‘normative’ (Wolfensberger, 1980) as she stands out in the crowd. Furthermore, unlike many other mothers in the UK, Rosie’s mother is unable to work full-time because of the lack of accessible and affordable childcare. The family is financially worse off than families without disabled children living with them with two parents working full-time. It could be argued that the family has yet to be empowered
Service providers' discourses

(with professional support) to lead a ‘normal’ life.

Website: http://autisticadvocacy.org/2012/04/autism-acceptance-month-essay/

Excerpt: Autism Acceptance Month Essay by Carol Quirk

I once thought autism meant a lot of inabilities: cannot talk, cannot switch topics, cannot give eye contact, cannot handle transitions or new routines, cannot read social cues, cannot control motor movements, etc. And I once thought some of the can-dos were not necessarily “adaptive” (as they say in the psychological and educational literature): perseverates on the same activity or conversational topic, gets anxious in uncertain situations, uses aggressive and/or destructive behavior, engages in self-injurious behavior. In my early days as a professional, I assumed – as too many people still do – that intellectual disability was a part of the package. So what happened to change my views on all of this? I got to know some autistic people who had acquired the ability to communicate, verbally or through pictures/typing, as well as some who did not yet communicate in any kind of traditional manner. I read the writings of autistic people. I listened to parents who said that, despite the testing results, they KNEW that their child was smart and understood what was going on. I listened to them say that their child was not only empathetic, but almost preternaturally so. I began to “presume competence” rather than make assumptions on face value. And I paid attention (or at least tried) in order to interpret meaning from the point of view of the people I met, not just from my own neurotypical point of view.

There are still too many people who make important life decisions FOR autistic children and adults based on limited understandings and prejudicial attitude. Too many professionals have not really known, loved, or spent personal time with an autistic person; but rather base their authority on their professional training alone. Non-autistic people need to know and be helped to
understand that our life experiences cannot be used to judge or value the behavior, appearance or needs of an autistic person. So that brings us to self-advocacy. We non-autistic people MUST listen and learn from those who are autistic. We must do what we can to support self-advocacy and dispel the myths about autism in the public and professional communities. The Autistic community must remain vigilant in its outreach, community education, insistence on “nothing about us without us,” and demand for inclusion in public policy decisions. Awareness of what it means to be autistic is still lacking for the world at large. Acceptance of autism as a natural condition in the human experience is necessary for real dialogue to occur. That is my hope.

Website: https://crackedmirrorinshalott.wordpress.com/2013/04/12/autistic-allistic-neurodiverse-and-neurotypical-say-what/

Excerpt: Autistic, Allistic, Neurodiverse, and Neurotypical: Say what?

Savannah Lodsdon-Breakstone

You’ll notice that I use “autistic” rather than “person with autism” throughout. This is intentional. The basic idea is that my being is autistic- the patterns my brain form thoughts in, essentials of the way I perceive and learn from the world are autistic. Autisticness is, for me and many others, an essential part of what makes me, me. Saying I am “with” autism denies this reality.

Allistic, on the other hand, means “non-autistic.” (Some people use “neurotypical” this way, but I’ll get to why I disagree with that usage in a moment.) That is all it means. It doesn’t mean someone is intrinsically better or worse, and it doesn’t indicate ally-hood or opponent-hood. It just means that someone is not autistic.
Neurotypical is often used interchangeable with allistic, but I would argue that it isn’t actually interchangeable. Neurotypical is short for “neurologically typical”- within the typical range for human neurology. Obviously it wouldn’t make sense to say that someone with definitively atypical neurology was neurologically typical just because their atypicality wasn’t that they autistic. Indeed, the Neurotypical/neurodiverse terminology has been adopted by certain segments of the Mental Health consumer’s/survivors communities for this very reason.

On-going usage aside, from what I recall the initial usage was one that is synonymous with the current “allistic.” However, between the acceptance of autistic cousins (those who aren’t autistic but who have similarities, including those with ADHD) and the penetration of the term beyond the initial communities it swiftly became used more diversely. Eventually, the more diverse (and in my mind accurate) usage meant that a more accurate term for non-autistic was needed. (Which brings us back to Allistic!)

Neurodiverse can have two meanings depending on what it is talking about. When referring to individuals, it simply means that the individual(s) in question have neurologies that are neurologically atypical. AKA, that they aren’t neurotypical. Generally speaking, this usage is not used to just talk about Autistics, but is inclusive of other people whose neurology is atypical.

This month is dually known as Autism Acceptance Month (by Autistics and our allies) and Autism Awareness Month (spearheaded by Autism Speaks, a cure-centric organization with little support from the Autistic community). Whichever you prefer to recognize, you have probably seen Light It Up Blue or a similar campaign by Autism Speaks, or read a news article about the “staggering” number of Autistics, and how our lives our so difficult.
You might even have been inspired by one or another of these campaigns, either this year or before, to consider altering your career path to do something to help “people with autism.”

We, the below signed members of the Stanford Autistic community, would ask you to reconsider. Many Allistics (people with an Allistic neurology; that is, people who are not Autistic) believe that they can help us through researching how to find “cures” or how to “mediate” the symptoms of Autism. Many will want to find the confluence of factors that causes a kid to become Autistic. Still others will be determined that they can further differentiate Autism (and Autistics) into a multitude of categories, in the hopes that more labels will somehow make us more self-aware.

We would ask: What does this work actually accomplish?

We do not need more labels. We do not need to know why we have a different neurology than you. And we certainly don’t need to know how to fix something that isn’t broken.

This and similar types of research achieve nothing but the continued marginalization of Autistics, and the perpetuation of stereotypes and myths about our “disorders.”

We are not disordered. We have a different neurology than you do, that can be fixed no more than yours can.

If you want to help Autistics, we encourage you to go into careers that will actually benefit us instead of trying to “cure,” “mitigate” or “eradicate” something we, along with many of our family members and our allies, consider a beautiful variation of human existence.

Go into researching the needs of Autistics at different ages, and how those needs can be met and accommodated as the person grows and enters school, college, the workforce and retirement homes. Develop classroom strategies that work in harmony with Autistics’ strengths and needs, which empower us to stim, instead of making us feel ashamed for being who we are. Build
cheaper and more accessible alternative and augmentative communication (AAC) devices for non-speaking or minimally speaking Autistics, to help translate their communication to others around them. Help parents understand that there is nothing wrong with them or their child, and teach them how to raise their child in an environment that is supportive, loving and nurturing to the child’s whole, Autistic self.
References


Landau, M., & Keefer, L. (2014). This is like that: Metaphors in public discourse shape attitudes. *Personality Psychology Compass, 8*(8), 463-473.


O’Brien, C. L., O’Brien, J., & Mount, B. (1997). Person-centered planning has arrived...Or has it? *Mental Retardation, 480*-484.


