

Spring 5-2015

Spoken Language to be Embraced and Avoided Around Disability: Words That Impact Identity and Sense of Achievement

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RUNNING HEAD: SPOKEN LANGUAGE TO BE EMBRACED AND AVOIDED
AROUND DISABILITY: WORDS THAT IMPACT IDENTITY AND SENSE OF
ACHIEVEMENT

Spoken Language to be Embraced and Avoided Around Disability: Words That Impact
Identity and Sense of Achievement

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PIM 72 J

A Capstone Paper submitted in fulfillment of the requirements for a Master of Arts in
Service Leadership and Management at

SIT Graduate Institute in Brattleboro,
Vermont, USA.

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ABSTRACT

The focus of this capstone is verbal language spoken to or about persons with disabilities. Language in this case study is discussed as words and phrases that are supportive and less supportive of how students see themselves, their identity, and sense of achievement. Three focus groups were held with students at Landmark College in Putney, Vermont to collect samples of their experiences and input their voices into this case study, adding value and depth to the existing literature. Disability is looked at through the lens of multiculturalism; as experiences that people with disabilities have with others and their environment are different than those of people who are able bodied, creating different cultural identities. This capstone defines disability, and perceptions of disability, as well as attitudes and the shift over time toward a social model of disability where it is viewed as a social construct: people are not disabled, rather, society is disabling. The history of education with a focus on disability is discussed with further attention paid to viewing education and language from the position of assets versus deficits. Pertinent questions around disability are addressed; do assumptions about the value of others follow from only partial knowledge of their abilities, allowing for less supportive language of their capabilities that put others down? Pertinent questions around disability are addressed; does less supportive language around disability stem from only partial knowledge about their abilities, and the assumptions that follow. Or can language change to become more affirming, as increased exposure to what we may not understand helps us to respect the differences and experiences of others more fully.

FORWARD

The motivation for this capstone has been my work with youth of varying abilities - either perceived or diagnosed, and identified with such labels as Autism Spectrum Disorder, Dyslexia, Attention Deficit Disorder, and Post Traumatic Stress Disorder, to name a few medical diagnoses. The students that I work with have told me stories about growing up struggling with school work, and about their relationships at school with one another and with their teachers. Several students in particular have helped me to learn more about what it means to be “different” from others and how it has impacted them. At first, I was uncertain how to respond to their stories of what teachers have told them or why they felt that going to school was pointless. I would affirm their statements, listen, and ask questions about how they could make things better for themselves if they felt the school wasn’t meeting their needs. I realized that I wanted to know more about their experiences and understand how others can be supportive of their experiences as well. Language became an important focus for me as I continued working with students and realized that words or phrases that others have said to them in the past carry a lot of weight over the years in determining how they feel about themselves today.

I recall times when I would get caught in a spiral of questioning the legitimacy of what the students were saying and assuming that they were exaggerating. I questioned whether I could say or do anything that would make things better or that would change their experience. Ultimately, I realized those assumptions were, and are, my expectations of “normal” social interactions that I have placed on the students based on my personal cultural values of how I believe things should be and how I would have acted were I in those particular situations. I viewed their values from an ethnocentric perspective of my own culture. The importance of

looking at their experiences from the perspective of multiculturalism, or multicultural education, as defined by Jesús and Johnson:

a perspective of disability that affirms the perspective of those who have the most direct experience - that is, people with disabilities, rather than promoting a dominant perspective of disability by external observers (2007, p. 4).

is a major motivation for this capstone.

As time went on and as I grew to know the students more, I increasingly began to understand their perspective as I also began to understand their environment. I noticed myself being careful to observe their actions, to note how they accommodated and adapted to their surroundings, and heard how they struggled and succeeded in achieving many goals they set for themselves. When things would become difficult for me in engaging with them, I personally struggled with how to describe what was happening in such a way as to not point out what was ‘wrong’ but what ‘could be’ based on what I already knew about them. I resisted the temptation to use words that would come easy to me: ‘don’t’ do this, or ‘stop’ that, or ‘why can’t you’ this. Through words like those, I immediately place an expectation of what “typical” interactions look like and therefore perceive a deficit in them when, in reality, I have already learned a lot about what they ‘can’ do. I have come to believe in my students, I realized I should focus on what they can do and talk more about that because I see it in them all the time.

This brought me to several questions: do we allow only our partial knowledge, through observation of others; govern our assumptions of their abilities and ultimately how we value them? Or do we take on the challenge to expose ourselves to what we know the least about - to know more about the life and childhood of someone who is different in order to understand those differences and their frame of reference? If I had not been willing to dig deeper and reflect on disability as a real life experience that many people live with, I may never have learned about

how important it is for me, as someone outside of their experiences, to begin to understand their culture and not place personal expectations from my own culture onto theirs. Instead, I challenged myself to learn more. What I learned helped me understand multiculturalism on another level.

INTRODUCTION

For this capstone, researching disability and education has become crucial to working with students who have learning differences and require extra support from teachers and counselors to achieve the standards set by the Common Core State Standard¹ (CCSS). Hearing from students about their experiences of struggling in school because many of their teachers teach in a singular style that may not be suitable for different learning-abled students, meant that learning more about education and disability in the United States is an area of research that will be outlined in this capstone. Investigation of the different perspectives on disability will shed light on where our current values of achievement and success come from and how that might impact the way we view success and which students we perceive as fitting that mold.

The major foundation for this capstone will be an exploration of Milton Bennett's *Developmental Model of Intercultural Sensitivity* and a look into multiculturalism with regard to disability as a culture unto its own with values and experiences different from those who identify as able-bodied. Furthermore, through this same lens of viewing disability as a culture, the perceptions we have about disability and how a created social identity conflicts with personal identity, labels, and stigma all interplay will also be explored. With regard to education, I will lay the foundation for asset vs. deficit thinking and how it can permeate our language, thereby

¹ **Common Core State Standard** is a rigorous set of standards for the English Language Arts and mathematics curriculum that has been developed based on the best practices of schools and organizations around the country and the world. Retrieved from <http://fsd79.schoolwires.net/domain/681>

affecting how students feel about their own identities and ability to achieve and succeed. The findings I learned from the case study at Landmark College, through three focus groups with students who identify with learning disabilities, will be discussed to further reinforce and enrich known knowledge with valuable student voices and experiences.

THE CASE STUDY

Permission to do this case study was approved by both Internal Review Boards of the School for International Training as well as Landmark College. A requirement at Landmark College was to work with a faculty member as a facilitator of this process. The facilitator's time and commitment helped this case study to be aligned with Landmark College's overall mission and vision as well as be beneficial to the students and faculty.

With the facilitator's support, I was able to introduce the case study and hand out letters of consent to about thirty-five students during the beginning and end of his two seminar classes. I spoke to the class in person about the focus groups, answered questions from the students, and received signed consent letters from those who were interested. These consent letters and the names of all the students who participated will remain confidential throughout the remainder of this capstone as part of the commitment to confidentiality of human subjects.

Following the introduction of the focus groups to the classes, organization of a quiet space in the Student Center of Landmark College was arranged for the meetings. Three focus groups of one hour to ninety minutes in length were held with two students each for a total of six student voices. During the focus groups the students were asked questions about their knowledge and experience with and of spoken language with regard to disability. Specifically, the goal was to learn what words and phrases, through their experience, they feel are supportive

or less supportive of their abilities. A sample question² asked was: “With your knowledge and experience, what words or phrases do you believe to be the most supportive and least supportive of ability and disability?”

THE PARTICIPANTS

Landmark College was selected as the main choice to conduct the case study for their reputation as being a highly regarded college for students with learning disabilities. During the first year at Landmark College, it is required that each student learns in depth about their disability and begins to understand how to work with it in their own way. My facilitator at Landmark teaches a First Year course and one of his focuses is language. I believe this made the focus groups significant, as the students had much to reflect on and the knowledge to speak about language around disability through the process of understanding their own disability.

The students who participated in the focus groups are all undergraduates of Landmark College over the age of eighteen. Of those who participated, one identified as female and five identified as male. Their disabilities ranged from physical to learning as well as intellectual. Several were diagnosed with multiple disabilities. The most common disability was Attention Deficit Disorder and Autism. Questions about their specific disabilities were not asked. Some of the students self-disclosed their disability as the focus group progressed and as the students became comfortable talking about their own disabilities in relation to the questions being asked.

DATA COLLECTION AND ANALYSIS

All participants will remain unidentifiable other than the fact that they are students from Landmark College and over the age of eighteen. Data collected for this case study included

² To view more questions from the focus groups, see Appendix A on page 53.

stories, reflections, and specific language (words or phrases) via various methods. Any physical notes taken or notes written by the students, were not and will not be shared with anyone nor shared online in any way. The entirety of each focus group was audio recorded and transcribed for analysis. To facilitate the analysis of the transcriptions, only responses that directly answered each of the questions asked were transcribed. In order to identify patterns, similarities, differences, and themes in the content, responses to each question from each focus group were transcribed in columns separated by focus group under the heading of each question. Analysis of the data was achieved by coding the responses into concepts and themes that emerged.

LIMITATIONS

Recognizing that this is a modest case study consisting of three focus groups with a student body at one institution of higher learning, there are limitations to this capstone. The voices captured within represent a small group of students with learning and physical disabilities that all attend an institution of higher learning that supports their capacity to learn about their disability in a safe and inclusive environment. Within Landmark College, they learn not only about themselves, but also about language, disability rights, access to accommodation, advocacy, and policy around disability. This well-rounded education on disability in a supportive environment builds confidence in the students that they can succeed once they move onto another institution or into a career of their choice. The students at Landmark were able to express their ideas, experiences, and thoughts around disability with eloquence and ease. This provided richness to the final capstone that was much needed in addressing language around disability. Nonetheless, the limitation remains that the voices included are minimal and come from one institution of higher learning where the students are expected to be achieve well-

rounded knowledge about disability. It would be another great case study to speak with students at other institutions where this may not be the expectation. Studies have been done at other institutions with a focus on disability and accommodation; none that were researched for this capstone however, have specifically focused on the use of language and multiculturalism.

USES

The intention in designing the focus groups and writing this capstone was to increase awareness around the daily effects that spoken language can have on anyone, but especially those with disabilities. It is important to be aware of our own identity within our society and which communities we identify with. Culturally, people with disabilities have different values, language, and experiences in life than people who do not identify with disabilities. This does separate us into different communities and cultures and therefore requires us to be aware of how our words can be supportive or less supportive of others in different cultural communities.

Campbell, Gilmore, and Cuskelly suggest:

It is of much greater importance to change attitudes towards inclusion as a result of becoming more at ease when interacting with people with disabilities, than to change attitudes towards inclusion as a result of perceiving the disability to be less of a barrier than originally thought (2003, p. 376).

Ultimately, this capstone is to serve as an additional source in the literature of disability studies, with the inclusion of much needed voices that identify with a disability. Their experience and knowledge can serve as a guide around the use of language and awareness for social service practitioners, teachers, professors, counselors, program facilitators; all who interact daily with people who identify with a disability.

DISABILITY

Johnson & Alexander (2004) wrote that there is no "...single, universally accepted definition of disability. Disability can be discussed in terms of specific physical, cognitive, and sensory attributes of an individual that limits one's ability to achieve personal goals" (p. 4). Some of the most common disabilities, listed by their medical terminology, include Blindness, Deafness, Paraplegic, Dyslexia, Dyspraxia, Attention Deficit Disorder, Down Syndrome, Autism Spectrum Disorder, and Obsessive Compulsive Disorder. These medical labels are *given* to individuals by society: and are used by doctors, psychiatrists and other service professionals to characterize them. Labels such as these that are given to people with any disability, may or may not align with how the individual views themselves and may result in a conflict within their self perception and how society views who they are. Especially as medical labels tend to use a negative, deficit oriented language ("cannot", "unable"), that identifies the disability as the fault of the individual for 'not achieving' 'normality'.

Vernon (1999) cites Hill-Collins (1990), in describing society as "implicitly hierarchical with one dominant group and several subdominant groups who define 'normality' according to their own interests so that there are degrees of 'normality' within one established norm" (p. 394). This definition can also be seen reflected in the Merriam-Webster's Dictionary (2014) definition of disability, especially 1(b):

1(a): a condition (such as illness or injury) that damages or limits a person's physical or mental abilities. **(b):** the condition of being unable to do things in the normal way: the condition of being disabled. **(c)** a program that provides financial support to a disabled person. **2:** lack of legal qualification to do something. **3:** a disqualification, restriction, or disadvantage.

“The condition of being unable to do things in the normal way” stands out as a chief attitude toward disability that on its own is disabling to many individuals who identify or are diagnosed with a disability.

In a manner of speaking, disability, and by its virtue ability, is something that can affect us all. Through sudden and unexpected accidents, people may lose the use of their limbs, or vision; war veterans or victims of crime or violence may suffer from trauma that affects their lived experiences; some disabilities are with the individual from birth; and of course, some people have different learning styles (visual, logical, etc.) that could lead to a label of “disability”. Disability theorists agree that if physical, cognitive, and sensory abilities and disabilities were viewed on a spectrum, we would find that we all are on a spectrum to varying degrees within every category imaginable. Yet the definition above is telling of the dominant perspective on disability: it minimizes the lived experience of many people who must accommodate to, adjust to, or live with the expected “normal” life that the able-bodied majority have created: e.g. walking up stairs, opening doors, sitting still for hours, seeing the black board, or hearing the teacher.

The definition is also largely based on disability as a ‘deficit’ and what others ‘can not do’ or are ‘unable’ to do. Jesús and Johnson (2007) write,

When disability is addressed, it is typically the prevailing deficit-based construction of disability that dominates the professional literature to the exclusion of the perspective of persons with disabilities as authentic representatives of their own experience...it represents a potentially ableist perspective of the disability experience (p. 3).

Charlton, a disability rights advocate, tells us “Beliefs and attitudes about disability are individually experienced but socially constituted” (1998, p. 51). Conflict can arise in viewing oneself as abled while society imparts labels that are ‘disabling’. Society, given its structure and its attitudes concerning disability, has made people with disabilities *feel* they are unable. What

society constitutes as ‘normal’, ‘typical’, or dominant is that which creates the barriers that those with disabilities have to work against, just to prove to others that their lived experiences are real and that they are capable. The dominant perspective sees disability as an obstacle to overcome while people with disabilities see society as the obstacle that creates the disability. In a study done by Olney and Brockelman (2003), individuals “viewed their disabilities as context-dependent and variable. They acknowledged the positive aspects of having a disability and frequently described disability as a problem in the environment rather than in themselves” (p. 39).

Goodley (2001, p. 222) makes mention that “Probing wider social reasons for someone’s actions opens up numerous causes” (as cited by Guskin, 1963; Koegel, 1986; Booth & Booth, 1992). With regard to viewing the actions of individuals who identify with a disability as valuable: that their interactions and experiences with the environment are due to dominant societal perceptions of disability, Gilson and Depoy (2000) quote Barnes and Mercer (1997) as saying that we may find:

Negative attitudes, limited physical access, limited access to communication and/or resources, and to the rights and privileges of a social group are considered as just some of the barriers that interfere with the disabled individual’s potential to actualize their desired roles (p. 208).

If society were to look inward at what is perceived to be the ‘problem’ for so many who identify with any disability, many social reasons would be at the core of what disability is: attitudes, misinformation, negative stereotypes, labels and stigma, and physical and political barriers.

IDENTITY, STIGMA, AND DISABILITY

Within a culture, individuals can identify themselves in many ways, or be identified by others with labels and identities that may or may be in conflict with how an individual sees

themselves. As mentioned previously, people who identify with a disability can also identify with and belong to other social and cultural groups. “Difference, defined as distinguishing features of groups that set them apart from one another, creates cultural boundary and juxtapositions, paving the way for identity” (Crow & Nind, 2006, p. 212). Within those groups, people develop their own identity surrounded by similar experiences and values. Gilson and Depoy (2000) quote Charlton (1998) when talking about where these lived experiences can occur for people with disabilities and how they serve to differentiate “...rather than being defined by imposed medical or functional terms, the common characteristics and experiences of disabled persons occur in the arena of political and social circumstance...” (p. 211). Gilson and Depoy also remind us “Cultural belongingness bestows identity, language and positions groups relative to one another” (2000, p. 211) and that identity is “The set of descriptors, characteristics and constants that one sees as belonging to him/herself, and that render one recognizable and unique to others (Gilson & Depoy, 2000, p. 210). By sharing a disability identity, collective group experiences are inevitable, and those in either the majority or minority group do not share the same lived experiences in either the personal, political, or environmental arena.

Social identity theory, as cited by Sidanius and Pratto (1999) in Olney and Brockelman (2003, p. 47), posits “interdependence between a person’s relationship to the in-group (i.e. majority culture), degree of identification with their particular out-group (i.e. minority culture), and the resulting power relationships.” Social identity theory also takes into account “...dominance and oppression without making the assumption that the oppressed group shares the perspective of the dominant group” (Kinzel, 1998; Olney & Brockelman, 2003, p. 47). Identifying oneself and belonging to a group is part of culture. People who identify with a disability can claim ownership of their own identity and belongingness. Meanwhile, dominant

cultures can also place persons into a minority group by prescribing labels and categories for differences that are both perceived and observed, and create a form of negative stereotyping that may well be in conflict with how individuals truly see themselves.

The term disability label is used to describe "...diagnosis imparted to participants by clinicians" (Olney & Brockelman, 2003, p. 35). However, the designation 'label' is used to distinguish the diagnosis from the individuals' actual experience of disability and self-perception (Olney & Brockelman, 2003). A disability label may or may not be in conflict with the identity someone has for themselves and how they see themselves interacting with their environment. Individuals who identify themselves within social and cultural groups of disability may also identify with medical terminology, which has little to do with their lived experiences. Many who have a disability label would consider

their disabilities as context-dependent and variable. They acknowledged the positive aspects of having a disability and frequently described disability as a problem in the environment rather than in themselves (Olney & Brockelman, 2003, p. 39).

Olney and Brockelman also quote that people with disabilities appear to adapt how they present themselves to specific situations. They might choose to embrace, reject, conceal, or reveal a disability for reasons other than fear or shame (2003). Students with a disability label, in studies done by Olney and Brockelman, show that they had to

negotiate the mixed or negative messages that resulted from disclosure. Students generally felt that others viewed them in a negative light because of their disabilities. They used such terms as lazy, substandard, and dishonest to describe what they felt were others' opinions of them (2003, p. 46).

Therefore, labeling and medically diagnosing disabilities have affects that are two fold. Many individuals do not know what, if any, disabilities they may have and have not been medically diagnosed. Others, they would say, are fortunate to know they have a disability that can help them to understand why they may seem to struggle at certain things while other

classmates do not and alleviate some of the internal conflict of not understanding their perceived difference. In the case of dyslexia, as Hammer studied “Some also valued having other students know they have dyslexia because it provides a positive, or at least less negative, message about the nature of their difficulties, which might otherwise be attributed to laziness, carelessness, or lack of intelligence” (2012, p. 4). This shows that knowing their medical diagnosis and talking about their learning differences benefit some students with disabilities. Medical labels may provide the person diagnosed with a disability label with better knowledge of their difference and relieve them of the stress that their difference is somehow their fault.

On the other hand, medical labels can be stigmatizing to the person with disabilities and is consistent with Bennett’s theory of negative stereotyping of a dominant and ethnocentric perspective. Shifrer (2013, p. 463) cites Major and O’Brien (2005) describing stigma, as “...prejudicial attitudes toward and negative treatment of people with characteristics deemed dangerous, undesirable, or unworthy.” When there is disclosure of a disability, further stigmatization and internal identity conflict can occur when others do not understand what their difference is, or what it means, and therefore judge their whole person based only on partial and perceived knowledge. Responses such as the one cited by Shifrer (2013, p. 463) in Aneshensel and Phelan (1999) --“Youth with learning disabilities are deviant in that they are sometimes perceived as lazy or stupid, just as the mentally ill were perceived as possessed or sinful, and distinctive because of their non normative response to educational response”-- illustrate some negative connotations and perceptions of medical disability labels. Edmonds (2012, p. 133) also mentions this impact in his work in saying that

It could be argued that labeling individuals as having ‘special educational needs’ or having a learning difficulty constructs and sustains exclusionary practices...by leading to the loss of identity of the individual and instead surrounding them with their disorder and assuming a deficiency or deviancy of some kind.

Edmonds continues this statement by comparing the labeling and using the individual deficit model as it “allows for the labels that convey negative connotations to remain, such as need, disorder, disability and special” (2012, p. 133).

Ultimately,

Given the highly stigmatizing potential of a category that is associated with deficit, it is hardly surprising that few individuals seek the identity for themselves. Instead the identity is commonly assigned and controlled by professionals and is based on ‘socially constructed criteria based on IQ and social functioning which identifies {individuals with learning difficulties} as needing special services. (McVittie et al. p. 4, as cited by Gilman et al. (2000) and Beart et al., (2005).

Shifrer (2013) researched many vignettes and videos of educators who perceived children with special education labels more negatively than unlabeled similarly behaving children (Allday et al., 2011). Edmonds also mentions that it’s important to consider the impact those teachers’ perceptions and attitudes can have on the peers of those whom they believe to have a disability:

If the peers are witnessing the child (with dyspraxia) being reprimanded by an authority figure for such things as slowness, messy writing, disorganization and inability to participate effectively in physical activities, then they may see the child as more of a target for victimization (2012, p. 130).

The first function of a label is to prove the disability is present and then to challenge the assumption of the correlation between that disability and the value, worth, and intelligence of that person as compared to the majority or ‘normative’ group. Labels and perceptions of disability, or challenges in being able to do things ‘normally’ have been proven to affect how students feel about themselves. Being labeled as disabled or ‘at risk’ is already stigmatizing. Add to that a further assumption that someone who has a disability needs to be *fixed* or is somehow *deficient* can lead students to think less of themselves and begin to believe that they are of less value and therefore strive less to succeed. Students who are placed in special education needs groups were found to have lower self esteem scores than students who were not labeled as

learning disabled (Hammer, 2012). Hammer, in her review of literature on labels and teacher expectations, writes about studies done in the 1970s that further explored this topic. She mentions a study in which evidence was provided “that knowing a child’s special education label affects teacher expectations for that child” (2012, p. 6). Hafner et al. also talks about how the deficit-thinking model can influence how educators and peers think about their students when they know their disability. One experiment found that “the label ‘learning disabled’ generates negative expectancies in teachers which affect their objective observations of behavior and may be detrimental to the child’s academic progress” (as cited by Hammer, 2012, p. 6). Further, studies that Hammer mentions go on to say “teachers perceived more deviance when the child was labeled learning disabled than when (he) was labeled normal” (2012, p. 7).

Further conflict with the given identity of a disability label is that some individuals would prefer that people not know about their disability for fear of how they may react or “have a negative view of their basic intelligence” (Hammer, 2012, p. 5). “What people object to in the use of these general terms are the misattributions that can be made...which could affect how others respond to them” (as cited by Hammer, 2012, p. 7). As cited in Hammer (2012, p. 7) a study by Jones in 1972 concluded that “students in the study reported feeling shame about being in special classes and not wanting other students to see them there; being made fun of; lying about what classes they are taking; having difficulties keeping a girlfriend and having concerns about negative impacts on post-school job placement”.

The lack of exposure and education of the very real diversity in a classroom can mean that students and teachers do not learn how to see each other as whole and appreciate their diversity and individual identities. It has been demonstrated that “The impact of the disability differed from situation to situation. It appeared that disability was normalized when students

were surrounded by others who experienced similar problems” (Olney & Brockelman, 2003, p. 39). Ultimately, as discussed in a later section, exposure to diversity can dismantle the idea that differences are a ‘problem’ within the individual and decrease the impact that this identification with a disability label can have on students and their view of themselves.

ASSETS VS. DEFICITS

In the case of students with a learning disabilities label, the labels tend to be perceived and categorized on the basis of a ‘deficit’:

and raise(s) the inference that an individual with learning disabilities will have deficits when compared against the ‘norm’. Conversely, a deficit in abilities when compared to the ‘norm’ infers an individual identity of having learning disabilities (McVittie, Goodall, & McKinlay, 2008, p. 6).

It is therefore not surprising that students tend not to label themselves with such a stigmatizing categorization (McVittie, Goodall, & McKinlay, 2008). Students who feel devalued and who hear constantly from teachers about where they are lacking, compared with their peers, even though they may have other strengths elsewhere can begin to feel *they* are not valued and may have lower standards for themselves and desire to achieve less.

Many classrooms today are structured in a utilitarian way and teach in a singular style that is designed to reach the greater number of students who are most likely to succeed, and currently, succeed in the growing technological economy. This marginalizes and devalues students who do not fit the ‘normal’ model of success in the traditional way. In educational settings, it is possible for educators to become stuck using medical terminology that may prevent them from learning and understanding that there is much more about their student’s identity than the medical label, and therefore an assumed identity, *given* to them.

When disability is addressed, it is typically the prevailing deficit-based construction of disability that dominates the professional literature to the exclusion of the perspective of persons with disabilities as authentic representatives of their own experience. This is very problematic because it represents a potentially ableist perspective of the disability experience, a perspective that multicultural education hopes to avoid (Jesús & Johnson, 2007, p. 3)

This ‘potentially ableist’ approach is filled with expectations and assumptions from an ableist perspective that can permeate language and instill in students the feeling of ‘not being good enough’ or not having their struggles acknowledged or respected. McVittie, Goodall, & McKinlay (2008, p. 4-5) cite Davies and Jenkins (1997) in their research finding that inevitably, “being categorized in terms of having deficits came to shape young people’s experience of self-identity across a range of social relationships.”

Hafner et al. says “The deficit-thinking³ model, at its core...posits that the students who fail in school do so because of internal deficits or deficiencies. Such defects manifest, it is alleged, in limited intellectual abilities, linguistic shortcomings, lack of motivation to learn and immoral behaviors” (n.d., p. 6). These assumptions stem from deeply set values where medical professionals, teachers, educators, or families may think of disabilities as needing to be cured. Further, this states that people with disabilities must resolve their own problems of accommodation and continuously be judged by others as not “fitting in”. Further, Hafner et al. (n.d., p. 7) also mention “The very process of labeling students as ‘disabled’ or ‘at risk’, for example, reinforces the assumption that school failure is due to internal student or family deficiencies”. A major drawback to this model, as summed up by McVittie, Goodall, and McKinlay (2008, p. 4) is it “...presents the learning disabled identity as one that is static and tells

³ One definition of **Deficit-Thinking** by the *Cramer Institute*: More of an emphasis on problems – motive is more to eliminate what we do not want, what we dislike, what we are disturbed by; focusing more on what is wrong; being vigilant about what is wrong; asking how we can eliminate problems. Retrieved from <http://204.200.153.100/ebeling/ABT.pdf>

us little about how that identity is managed in everyday social contexts.” Adams et al. (1997) and Young & Laible (2000) (as cited in Hafner et. al, n.d., p. 8) summarize: “deeply held beliefs and assumptions about students and families impact how educators engage in their work.” This can lead to blame and victimization of the person with the label. Simultaneously, the label can deflect the professional from responsibility they may have as educators for equal access to education and feel that the student with a given label needs to be *fixed*, that they have *deficits* to be filled, or that they must find their own way to solve their struggles.

Harry and Klingner, when writing about IDEIA and how its main criteria for services eligibility has been “*proof of intrinsic deficit*” (2007, p. 16) agree that there are two problems with this focus: “Plagued by ambiguous definitions and subjectivity in clinical judgments, these categories often have more to do with administrative, curricular, and instructional decisions than with students’ inherent abilities.” In other words, the problems with the criteria are that they are subjective and clinical, and take away anything that is human about the student and their true abilities.

In writing about coming to understand the culture of disability and deafness, authors Johnson and McIntosh (2009, p. 77) summarize the importance of riding our language within the education system of deficit thinking:

Youth with disabilities are taught that others devalue characteristics and features that make them who they are and that adopting, assuming, and demonstrating the features, characteristics, and identity of a nondisabled person is a priority of many educational and service delivery practices. Over time, many Disabled or Deaf persons begin to realize that they have been taught to devalue and rid themselves of undesirable characteristics that are essential and integral elements of their life experiences and their identity (p. 77).

With a focus on looking for assets in students and using positive reinforcing language can bolster self-esteem and guide students to recognizing their potential, even if it leads to non-traditional paths or models of success. An asset based approach or strengths based approach was developed

in the 1990s when counseling went through a paradigm shift from the medical model, focusing on scientific causes and effects, to the strengths based model focusing on their assets (Weishaar, 2010, p. 207). Recognizing that students learn differently is also an important aspect in multicultural education:

Recognizing different learning styles within the education system would mean that instead of being left flailing in an environment that is geared towards the neurotypical world these children could benefit from learning techniques that fit and make sense to their learning style, building on their strengths and raising their self-esteem (Edmonds, 2012, p. 134).

Access to potential is as important as access to education; indeed, educational settings are where students learn to realize their potential and build on their strengths, not just focus on perceived or *given* deficit labels.

THREE MODELS OF DISABILITY

One way to begin understanding the complexity of perceptions and attitudes regarding people who identify with disability and disabilities in general is to review the history of attitudes toward disability. Throughout history, disability has been viewed through different lenses, or models. There are three different models of disability⁴ and throughout history the shift in perspective has moved from a moral, to a medical, to a social model as noted by Johnson & Alexander (2004). The moral perspective on ability and the perception of disability has “dominated ‘western cultures’ for 300 years” (Johnson & Alexander, 2004, p. 4). The moral, perspective holds the view that disability is a “special gift” and responses toward those who have disabilities ranged from persecution to charity or pity, as cited by Johnson & Alexander (2004). This is the oldest perspective of disability because it encompassed a time period when

⁴ For a visual representation of these three models, visit Appendix B on page 54.

“explanations of disability were rooted in religious beliefs, superstitions, and other conceptualizations” (Johnson & Alexander, 2004, p. 4). Churches and religious faiths dominated moral values, which led to feeling pity for others, or viewing their struggles as personal and a burden handed to them from an external power or being.

Viewing disability as a “special gift” is still prevalent today. People with disabilities are part of the diversity of humans; to say that all people with disability have a “special gift” is to still look at the disability with the perspective of inspiration and something to be commended for overcoming or working with. This leads to the question of who accommodates so as to remove barriers to equal access so disability is not something to overcome or struggle with.

Encapsulating this perspective, Crow and Nind (2006, p. 6) say that,

These interpretations impose narrow assumptions about the varying experiences of impairment and isolate experience from its disabling context. They also segregate us from each other and from people without impairments. Interpreting impairment as personal tragedy creates fear of impairment and an emphasis on medical intervention. Such an interpretation is a key part of the attitudes and actions that disable us.

This moves the discussion onto the medical model of disability. In the United States, as in many medically and technologically advanced nations, ability and disability is strictly categorized and classified. There is specific language, labels, characteristics, and practices around disability in the medical field. Gilson and Depoy define the medical model as

A medical approach to disability defines disability as a permanent biological impediment and positions individuals with disabilities as less able than those who can recover from illness or who are non-disabled...the focus of disability is on physical, behavioral, psychological, cognitive, and sensory tragedy” (2000, p. 208).

The medical perspective of disability comes in the form of a many diagnoses for hearing impairments, learning disabilities, or mental and developmental disabilities. “It emerged out of the growing knowledge of the human condition and early medical advances and treatments during the Renaissance” (Johnson & Alexander, 2004, p. 5). The medical model segregated

people with disabilities into institutions, asylums, and even within hospitals. The emphasis of this model was placed on physical needs and where a group of people was deemed necessary to oversee individuals with disabilities. As Johnson & Alexander (2004, p. 5) mention, "Disability was regarded as a medical issue that could be best managed by trained medical professionals." Within this framework "...the medical model of disability, a person's functional limitations are the root cause of any disadvantageous experiences and these disadvantages can therefore only be rectified by treatment or cure" (Crow & Nind, 2006, p. 3).

Crow and Nind continue to discuss further that at its most basic level impairment, and disability, is an objective concept. Simply, it means,

...that aspects of a person's body do not function or they function with difficulty. Frequently, this is taken a step further to imply that the person's body, and ultimately the person, is inferior. However, the first is fact; the second is interpretation (2006, p. 6).

Which leads to the discussion of the last perspective of ability and disability, the social model.

This perspective brings our attention to focus on what is around us as Crow and Nind would describe, "...disabling social, environmental, and attitudinal barriers rather than lack of ability" (2009). They further talk about how they and their bodies were not responsible for their difficulties, but that:

it was external factors, barriers constructed by the society in which I live. I was being disabled - my capabilities and opportunities were being restricted - by prejudice, discrimination, inaccessible environments, and inadequate support. Even more important, if all the problems had been created by society, then surely society could uncreate them (Crow & Nind, 2009, p.1-2).

The social model is increasingly questioning what is 'normal,' which leads to the question of what are we 'fixing'? If there is anything to be 'cured' there has to be a comparison being made to something that is believed to be ideal or 'normal'. The social perspective looks into this idea of where the systemic ideals of 'normalization' stem from and how it's being perpetuated. The

core belief of the social perspective is that the challenges facing people with disabilities are a result of prejudice and discrimination to our human differences and diversity. Summing up this idea, Gibson, (2006) remarks

It is via 'universalized' reason, i.e. modernist legitimate knowledge as emergent from the dominant social group, that society created the child, adult and/or organization in need of rescuing; the 'school leaver', the 'failing' school, the 'disadvantaged', the 'at-risk', the 'displaced', the 'dysfunctional' (p. 320).

The social model is slowly making progress in shifting from exclusion of human diversity as in the moral model of segregation and into inclusion and integration of diversity. This means that the focus is on altering and adapting communities and societies to fully include people with disabilities. Gilson and Depoy (2000, p. 208) quote Barners and Mercer (1997) illustrating the concept of the social model:

Negative attitudes, limited physical access, limited access to communication and/or resources, and to the rights and privileges of a social group are considered as just some of the barriers that interfere with the disabled individual's potent to actualize their desired roles.

This includes shifts in attitude, language, and accommodation to perpetuate full access, rather than labeling, diagnosing, and attempting to 'cure' individuals of being 'unable to do things the normal way'.

HISTORY OF EDUCATION AND DISABILITY IN THE UNITED STATES

Values and perceptions about people who have disability identities and their education go back to the early 1800s where, in the United States, it began with optimism for their reintegration and rehabilitation. However, as the United States became more urbanized in the later half of the 1800s, that optimism began to fade. Employment increasingly began to rely more heavily on

intellectual ability and less on physical labor. Therefore, people with intellectual disabilities⁵ were “less able to adapt to an increasingly industrializing nation” (Harbour & Maulik, 2010, p. 3). Furthermore the, “progressives’ ideal of training, rehabilitation, and reintegration proved to be disillusioned: people could learn skills, but did not attain “normalcy⁶” (Harbour & Maulik, 2010, p. 3). As optimism dwindled, so too did the systemic rehabilitation and reintegration programs that were thought to be successfully growing. Alongside, the medical perspective started taking hold as urbanization led society to believe that people with disabilities were the cause of poverty, laziness, illness, and crime. Soon thereafter, an alarmist attitude and fear toward people with disabilities grew out of a discovery that many disabilities were hereditary. To decrease the likelihood that people with disabilities would reproduce and to “protect normal society” they were segregated into institutional settings and their reproductive lives controlled.

Since the emergence of psychological testing in the early 1900s, the identification, labeling, and diagnosing of children and adults with disabilities increased (Johnson & Alexander, 2004). Segregated institutionalization also saw a steady incline during this time period. By the 1930s and 1940s, more advanced research began to disprove the heritability of disabilities as studies of institutionalized people were proving that more than half of them had parents without disabilities (Harbour & Maulik, 2010). By the 1960s, President Johnson’s War on Poverty and the establishment of the Project Head Start sought to address some of the environmental causes of disability. These projects proved that the knowledge of disability was changing from a moral to a medical perspective and also away from the false assumption that disabilities were hereditary or the cause of many social injustices.

⁵ Harbour & Maulik (2010) use the term ‘intellectual disability’ to refer to a wide variety of learning and cognitive disabilities.

⁶ Recall “**Normalization**” defined by Johnson & Alexander (2004) as “making available to individuals with disabilities patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream society”.

Education became involved in decisions regarding disability during the 1950s and 1960s. In 1954 the United States Supreme Court decision of *Brown vs. Board of Education* ruled that separate schools for colored and white children were inherently unconstitutional. This legal milestone in time was a catalyst for the disability rights litigation, as there were similarities that the racial and disability rights movements faced with regard to discrimination, segregation, and exclusion. Later, in 1975, the Education For All Handicapped Children Act (later renamed in 1990 as the Individuals with Disabilities Education Act [IDEA] and now the Individual With Disabilities Improvement Act [IDEIA] in 2004) extended a free and appropriate public education to all children demonstrating educational need. This act was amended in 1997 and promoted access to general education for students with disabilities. Also in the 1970s, the Rehabilitation Act of 1973 ruled that programs for children or adults receiving federal funds must make “reasonable accommodations” to enable the participation of individuals with disabilities. This established that the state make accommodations to people with disabilities and became an important principle in disability rights law.

In 1999 the United States Supreme Court stated that the segregation of individuals with disabilities in institutions might constitute discrimination based on ability. The court then required that states provide community services rather than institutional placements for people with disabilities. Many of these cases show that accommodation to, access for, and integration is supported. The progress is, however, slow and the implementation is rarely encouraged.

Within the classroom, educational professionals questioned the rigor and direction of curriculum and instruction. This topic dominated the educational discourse after the launch of the Sputnik satellite by the Soviet Union in 1957 as cited by Osgood (2005). It required that students with disabilities participate in state and local standard based assessment programs as

well as required states to develop improvement plans with school and community involvement. Currently, the No Child Left Behind Act (NCLBA), IDEIA, and Common Core State Standards (CCSS) are aligning with each other given the federal legislations' requirements for students with disabilities to be included in state accountability systems (Katsiyannis et. al, 2007). This increases accountability for all students, including those with disabilities to achieve the same standards through narrow assessments, exit exams, and measurement scales. IDEIA also requires children with disabilities be included in all general state and district-wide assessment programs, with appropriate accommodations and alternate assessments where necessary (Katsiyannis et. al, 2007). Where appropriate, alternate assessments are used to demonstrate proficiency in advanced subject matters with students who have severe cognitive difficulties. These alternate assessments can include portfolios, rating scales, checklist approaches, and evaluation of performance tasks (Katsiyannis et. al, 2007, as cited by Roach, Elliott & Webb, 2005).

Given the potential negative consequences these assessments have for all students, participation of students with disabilities in these assessments have been controversial (Katsiyannis et. al, 2007). As cited by (Jimerson, Anderson & Whipple, 2002) in Katsiyannis (2007, p.161) "...research has shown that retention is an ineffective means of remediation and has an adverse impact on long-term student success." Katsiyannis also quotes Ownings & Magliaro (1999, p. 162) as saying:

In the long term, retained students tend to have poor adult outcomes, including earning low wages, experiencing high unemployment, and being prone to ending up in the criminal justice system. Indeed, retention in any grade has been linked to high dropout rates, produced negative social implications, and resulted in lower academic achievement.

EXPECTATIONS OF SUCCESS AND ACHIEVEMENT

Education has changed from being a place where students would learn how to be a part of the labor force to being taught intellectually based studies. In the United States, teaching in the classroom is based heavily on logical-mathematical and linguistic⁷ learning and teaching styles as Edmonds (2012, p. 133), citing Ornstein (1997) who provides such evidence:

Most education is delivered in logical sequential form, which matches the learning/thinking styles of those children who are left-brain dominant. This emphasis in the education system would also explain, to some extent, the teacher's lack of understanding when faced with a child who thinks differently due to their training being for more left-brained, logical, sequential teaching.

This excludes other aspects of intelligence to favor those that would be of higher value in a growing global economy. Haager and Vaughn (2013) make a similar statement:

The intent of the CCSS document is to outline a rigorous course of study that will best prepare America's youth for the global economy. Certainly, college and career readiness is an important long-term goal for students with LD⁸. Yet, it is widely known that literacy - particularly reading and writing are areas of serious difficulty for the majority of students with learning disabilities. Increasing the rigor of K-12 expectations is likely to present increased challenges for students with LD and their teachers (p. 6).

With an emphasis on teaching students a curriculum based mainly on mathematics and linguistics, exclusion is highly inevitable and it could be argued that students who learn differently are being discriminated by the education system and seen as 'deviant', 'lazy', or 'incapable' (Edmonds, 2012).

When discussing achievement and success with regard to education, one route is to look at the definitions provided by the Merriam-Webster Dictionary. Their definition of achievement is as follows: "**1:** the act of achieving: accomplishment, **2 a:** a result gained by effort, **2 b:** a great or heroic deed, **3:** the quality and quantity of a student's work" (2015). Success is defined

⁷ According to Howard Gardner there are seven types of intelligences: Visual-Spatial, Bodily-Kinesthetic, Musical, Interpersonal, Intrapersonal, Linguistic, and Logical-Mathematical. Each are distinctively different and students learn on a spectrum through all of these types of intelligences.

⁸ LD, as used by Haager and Vaughn (2013), is an acronym for Learning Disability

as: “*Obsolete*: outcome, result, **2** a: degree or measure of succeeding b: favorable or desired outcome; *also*: the attainment of wealth, favor, or eminence, **3**: one that succeeds” (2015).

When initially reading at these definitions, some may think they are true and perhaps objective.

However, upon more critical reading, there may be an understanding that these definitions are entirely subjective to the person deciding what it means to achieve to succeed in something.

This brings to the surface the idea of ethnocentric values from Milton Bennett’s model of Intercultural Sensitivity (to be discussed in the following section): values and ideas of success and achievement are individually based and different across cultures.

Naturally, for some successes and achievements to be valued over others, there must be a reference point being used as a benchmark of success and achievement. Within an educational setting, students with and without disabilities are being assessed and identified as meeting special education requirements by their teachers. How do teachers identify which students are succeeding in the mainstream classroom and which are not? Campbell, Gilmore, and Cuskelly quote:

Teacher judgments of acceptable student achievement or behavior are necessarily based on the performance of the teacher’s particular referent group, which naturally consists of the other students in the school. Thus, the student’s peers within his or her school provide the normative standard for identifying whether the student is disabled and so is eligible for special education (Hibel, Farkas, & Morgan, 2010, p. 315).

Further, in researching the attitudes of teachers toward disability, Forlin et al., (1996) as cited by Campbell, Gilmore, and Cuskelly suggest that “...negative attitudes ‘lead to low expectations of a person with a disability’ which in turn could lead to reduced learning opportunities, beginning a cycle of impaired performance and further lowered expectations, both by the teacher and the child” (2003, p. 65-66). Gilmore et al. have similarly proven throughout their research that “...community knowledge and attitudes are important determinants of the acceptance and

support that people with disabilities receive, and the opportunities that are available to them within their communities” (2003, p. 67).

MULTICULTURALISM

Cultural views of disability suggest that all individuals who define themselves as disabled belong to a unique group, which shares experiences, tacit rules, language and discourse. In this view, the notion of disability is one of group belongingness and distinction from other groups who do not share the disability identity (Mackleprang & Salsgiver, 1999 as cited by Gilson & Depoy, 2000, p. 209)

Initially, individuals who have a disability and individuals who are able bodied may be thought of as belonging to the same culture. They may reside in the same communities, attend the same churches, and visit the same libraries and markets. People who have disabilities can also identify themselves within other social categories, as people who are able bodied can: political and religious views, skin color, gender, socio-economic class. etc. However, interactions with others and the environment, how we function and what is accessible in terms of services, housing, and education can be markedly different between people who are able-bodied and people who identify with a disability. Bluntly, Johnson and McIntosh make a point in their article about cultural perspectives on disability:

When studies consistently report that significant proportions (e.g., 30% to 85%) of a population experience specific social, economic, employment, and/or educational outcomes of interest, it may be concluded that such outcomes are indicators of a “shared” or “collective” group experience that contribute to an emergent or established culture (2009, p. 71).

Tirmizi defines culture as “...shared ways of thinking, feeling, and behaving rooted in deep-level values and symbols associated with social effectiveness, and attributable to an identifiable group of people” (Halverson & Tirmizi, 2008, p. 11). For people with disabilities, ways of thinking, feeling, and symbols, including language: “Language is the set of symbols that

describes, sorts, classifies, and provides the forum for sharing individual experience” (Rogers, 1996 as cited by Gilson & Depoy, 2000, p. 212) are different than for people who are viewed as able bodied. Johnson and McIntosh (2009, p. 69) also describe disability as a culture of its own:

A person’s particular and individual culture is the unique synthesis of all the characteristics and experiences that shape how one views the world and how the world views and interacts with the individual. Thus, the cultural aspects of Disability and Deafness are undeniable; they shape how individuals experience the world and how the world responds to and shapes the individual.

We perceive the world through our own eyes and frame of reference, an ethnocentric perspective. Yet, our world can be just as culturally different as the person next to us. Viewing disability through a social lens highlights the importance of including people with disabilities as a part of the fabric of what creates multicultural communities. Their experiences are different from those of able-bodied individuals, and to cluster them together would be to minimize their differences and experiences; “...each experience is individually characterized by a common history, collective identity, and shared values and experiences of group members that are frequently expressed in art, music, literature, sports, and more recently through scholarship and Internet technologies” (Johnson & McIntosh, 2009, p. 71). Students in studies by Olney and Brockleman have also expressed “...awareness that they shared with others who have disabilities a unique experience that is not available to the majority” (2003). Statements like this illustrate how from the perspective of individuals with specific lived experiences often do not share those experiences with others. Further statements from other writers on disability rights state similarly, that:

Cultural views of disability suggest that all individuals who define themselves as disabled belong to a unique group, which shares experiences, tacit rules, language and discourse (Johnson & McIntosh, 2009, p. 75).

Perhaps disability is a foreign concept or idea, just as cultures in other parts of the world

can be. Disabilities can be both hidden and visible. Hidden disabilities run the risk of being minimized by the perspectives of those who are unaware of their existence while disabilities that are visible are in danger of being isolated and segregated. Dominant able-bodied individuals with little exposure to these differences may not know how to interact with others who are perceived as different, or perhaps run the risk of minimizing their experiences through a lack of awareness. By the nature of certain values and worldviews that have become the dominant culture of ableism, our expectations and ideals we place on others also align with that dominant abled perspective:

The argument is formulated that ‘valid’ knowledge is socially constructed, emerging from the values, attitudes, opinions and/or ideas of the dominant social group. This, it is suggested, leads to the exclusions of other forms of knowledge, resulting in the creation of ‘outsiders’ (Hughes et al., 2005 as cited by Gibson, 2006, p. 65).

Hill-Collins (1990) as cited by Vernon (1999, p. 394), makes a similar point when saying, “We live in a society, which is implicitly hierarchical with one dominant group, and several sub-dominant groups who define ‘normality’ according to their own interests so that there are degrees of ‘normality’ within one established norm.” Ultimately, this perspective perpetuates the dominant worldview and threatens to deprive others of their own personal cultural identity and belongingness:

Cultural belongingness bestows identity and language and positions groups relative to one another. Cultural belongingness bestows collective and community where one did not previously exist and cultural belongingness distinguishes communities from one another (Gilson & Depoy, 2000, p. 211).

It is important to view people who have a disability as having their own culture, community, and life meaning that are different from those of able-bodied individuals. This provides them with the possibility to create their own social identity, language and symbols. All

too often, dominant groups are full of suggestions as to what people with disabilities should call themselves. Heumann (1993), as cited by Gilson and Depoy (2000, p. 212) argues “these euphemisms have the effect of depoliticizing our own terminology and devaluing our own view of ourselves as disabled people”. Thus, “choice of language and labels that emerge from within the disability community creates bonds to counter derogatory and oppressive language used by those external to the disability culture to describe disabled persons” (Gilson and Depoy, 2000, p. 212).

FROM ETHNOCENTRISM TO ETHNORELATIVISM

It would be valuable to deepen the understanding of the three models of disability, identity, and multiculturalism by exploring Milton Bennett’s Developmental Model of Intercultural Sensitivity⁹. In this model, Milton Bennett describes and analyzes various stages of multicultural readiness that individuals progress through: from the denial of differences that exist to the minimization of their importance, all the way to acceptance and integration of differences into everyday life.

To begin, Bennett defines two stages of perceiving the differences in the world around us. His definition of “ethnocentric” is “assuming that the worldview of one’s own culture is central to all reality” (1993, p. 10). This idea aligns and parallels with the idea of “egocentrism”, where people can tend to assume that their experience is equal to the experiences of others. Central assumptions such as these are the roots to negative perceptions and evaluations of others, other cultures, other races, and the creation of dominant and minority groups. The observation of

⁹ Visit Appendix C on page 56 for a visual representation of Milton Bennett’s Developmental Model of Intercultural Sensitivity

differences with regard to disability and the assumptions made from ethnocentric perspectives can minimize differences and the meaning people with disabilities have created in their lives.

Discriminatory interactions, patronizing responses of others and labels with negative connotations can all be considered as structural ableism, which can lower self-worth and lessen a sense of intrinsic values (Thomas, 2007 as cited by Edmonds, 2012) and it is suggested that this can re-injure the 'self' through internalizing discriminatory values (Marks, 1999 as cited by Edmonds, 2012, p. 133).

Milton Bennett would describe this thinking and behavior in his Developmental Model of Intercultural Sensitivity as denial: "a purely ethnocentric person simply does not consider the existence of cultural difference. A person at this stage of development believes that cultural diversity occurs only elsewhere" (1993, p. 10). Being in the denial stage of intercultural sensitivity, according to Bennett, can emerge in one of two ways: isolation from differences, or separation from them. Both of these circumstances exist with regard to disability. Through denial, able-bodied individuals can easily separate from, and not be exposed to, both apparent and invisible differences of people with disabilities. Physical separation can foster the denial of the existence of differences. Bennett describes separation as the "intentional erection of physical or social barriers to create distance from cultural differences as a means of maintaining a state of denial" (1993, p. 11). This can be thought of, with regard to disability, as students in special education settings apart from students in the mainstream classroom or individuals who have disabilities living in housing that is accessible, yet separate from other housing settlements. From the perspective of separation, if cultural difference is not experienced at all, as Bennett describes, it simply has no meaning; if cultural difference were experienced within the context of denial, differences would be overlooked through the process of "selective perception" or "only that which is already familiar is perceived" (Bennett, 1993, p. 13).

Moving from a state of denial there is defense. Bennett describes defense as a “posture intended to counter the impact of specific cultural differences perceived as threatening. The threat is to one’s sense of reality and thus to one’s identity, which...is a function of that one cultural reality” (1993, p. 13). Being in the state of defense means differences can be looked at negatively and as a threat to how one sees their reality being shaped by the perspectives of others. The most common strategy to counter the threat of differences, Bennett mentions, is denigration: or evaluating those differences negatively. The process of doing this is generally called “negative stereotyping”. Considered “negative stereotyping” with regard to disability is: labeling and derogatory language being used to describes “others” who are different from the self. Alongside negative stereotyping is the creation of rationales for the groups’ inherent ‘inferiority’, or the medical model dominant perspective that individuals with disabilities needing to be ‘fixed’ or ‘cured’. Movement beyond denial, defense, and isolation is obstructed by institutionalized and societal creations of differences as negative and threatening to a dominant way of life. With regard to disability, medical labels and classroom separation only perpetuate the likelihood that people who have disabilities will be perceived as different from, inferior to or less than, and separate from others.

The last stage of Bennett’s model within ethnocentrism is minimization. Bennett would describe this as the “last attempt to preserve the centrality of one’s own worldview...an effort to bury difference under the weight of cultural similarities” (1993, p. 21). Differences are not negatively evaluated; rather, they are trivialized, or minimized. While differences are seen and awareness of their existence is present, they are seen as relatively unimportant. In this state, human similarities are seen as more powerful. At the expense, however, is denying differences and the reality of their existence in the lived experiences and interactions with others and the

environment. What makes this state so attractive, is that the assumption that all people share similar motivations for achievement, as Bennett describes. However, these assumed characteristics are usually derived from a dominant culture group.

Shifting from states of ethnocentrism to ethnorelativism requires individuals to be aware of differences and not rest in a state of minimization of differences by viewing them as insignificant. In order to shift toward ethnorelativism, difference needs to be experienced and acknowledged as non-threatening to our own perspectives and way of life. Central to ethnorelativism is the idea that difference is neither good nor bad, that it is just that, different. One's own culture is not any more central to reality than that of any other culture, as Bennett describes. Taking the time to expose us to more and learn new things can enrich our experience of others. It does, however, raise some questions that are important to look into: does becoming ethnorelative imply that individuals morally comply to other ways of life not their own? Bennett (1993) attempts to answer this question by stating:

Ethnorelativism does not imply an ethical agreement with all difference nor a disavowal of stating (and acting upon) a preference for one worldview over another. The position does imply, however, that ethical choices will be made on grounds other than the ethnocentric protection of one's worldview or in the name of absolute principles (p. 27).

This means that a change in perception of difference must arise within the individual. First, comes respect for cultural differences, followed by respect for cultural differences in values. This is when people see differences as indicative of deeper meaning and cultural ways of life and creation of meaning within lives. "Rather than being evaluated negatively or positively as part of a defensive strategy, the existence of difference is accepted as a necessary and preferable human condition" (Bennett, 1993, p. 28). Further, Bennett describes that what is intrinsic to this stage is the belief that values and assumptions are not just things so much as expressions of human creativity. He continues by describing that we do not *have* values, we

create values by the way we organize and interact with the world as we see it. It is important that we recognize that we all participate in the organization of the world around us through our own perspective of it and that it is a process which we all go through: through valuing certain things, they then become values we hold.

With regard to pluralism, Bennett suggests that cultures are seen as “not only different, but that such differences must always be understood totally within the context of the relevant culture” (1993, p. 35). This means that an understanding of difference derives from actual experience within a full cultural frame of reference. Pluralism, can therefore, be the umbrella category under which “biculturalism” and “multiculturalism” are contained. To develop multiple cultural frames of reference requires exposure to and living experience in or with another culture. To Bennett, “pluralism represents a development of intercultural sensitivity beyond empathy” (1993, p. 35). In this form, cultural differences are seen and as highly respected as one’s own, and is part of the integration stage of Bennett’s model. With regard to disability, this stage requires exposure to individuals who have identified with disability and respecting their experiences belonging to their own culture for their set of experiences, values, language, have all been part of their world view and are different from the majority.

Thus far, the stages of ethnorelativism have emphasized that differences are not evaluated. Holding evaluation was integral to crossing the line from ethnocentric stages. Bennett continues discussion of acceptance in the ethnorelative stages with what he calls “Contextual Evaluation” of differences. This is important with regard to disability as those individuals, who are capable of evaluating their own culture, whether dominant or oppressed, can do so without rejecting their own entire culture or that of the other. Contextual evaluation requires the ability to recognize there are differences, and self-awareness that we are a part of

those differences. Therefore, minimization of worldview, values, and meanings created in the lives of others is limited. Edgar et al, as cited by Johnson and McIntosh (2009, p. 68) concluded that the "...knowledge, values, attitudes, and awareness required for cultural competence cannot be imposed but must be experienced, developed, and owned."

LANGUAGE AND DISABILITY: FOCUS GROUP FINDINGS

The focus groups were full of insight into disability as a culture, with a lot of focus on language as being culturally significant as well as specific experiences as being distinguishable from groups that set them apart, creating their own disability identity. The findings all tie into the social theories of disability as defined by Olney and Brockelman. In all three focus groups, when asked the first question about an event at school when someone acknowledged them for their strengths and achievements, the students mentioned the word 'praise' in many of their narratives. There was praise for improvement of grades, praise for high grades overall, praise for doing well with so much responsibility, and praise for doing things well when those acts may have gone unnoticed or overlooked had it not been for that teacher at that time.

Other language that specifically stood out to students within the scope of the first question was ideas and phrases such as: 'grateful', 'keep on trucking', and 'way to go'. The grander meaning of why these stood out when looking at the focus groups data, was that for all the students who talked about praise, they also mentioned the idea of improvement and progress. That without notice of the improvement or strides being made, alongside the acknowledgement of their particular disability, none of what their teachers could have said would have made a difference. One student said that the most important thing he remembered being told was to "...look at everything you have done". Others mentioned, "I felt like I accomplished something

pretty amazing.” Progress was again visited as a feeling combined with increased confidence, “I gained confidence cause I knew I could succeed and continue to succeed” and “hearing that I could succeed made me want to push more”. The sense that “you are succeeding” or you “have succeeded” rather than “reach for success” stood out to the students in that “the actual having accomplished something or saying that you are doing well or that you did do well” is where the connection to progress and accomplishment lies. The fact that success can be seen “as a noticeable progression” a “reinforcement” that progress is possible “If you already know you can do it once you know you can do it twice”. This was a definite theme as many of the students talked about their own individual struggles and how they overcame them differently based on their unique disability.

The ideas and language around progress is echoed in the ideas around assets and deficits. To be reminded of their progress is to be reminded of their assets and strengths rather than deficits. This helped students to believe in the possibility that they ‘can’. Overall, the students agreed that the capturing of what was being done well “felt nice” because “it was something I had not heard before”. With regard to how these words made them feel about themselves, students in all of the focus groups talked about a sense of ‘relief’ - relief from their experiences of struggle, and the feeling that their effort was worth the while.

The topic of assets and deficits were again addressed in terms of describing the “human potential” as “extraordinary”, that people can do great things. However, the way that potential is cultivated is in the way it’s addressed so as not to “prune people” by focusing on their deficits and having expectations that: “if you don’t have this stuff (certain assets) it’s not going to work for you”. Students talked about how they “Might be weak in some areas. But we are actually kind of strong in others. People don’t really express those strengths, they only identify those

weaknesses.” This summarized the importance of supportive language around the focus of strengths, ability, and assets and paralleled the thoughts of Jesús and Johnson. To highlight this, one final quotation was “Better to know your strengths and your weaknesses. Don’t just embrace your weaknesses.”

The ways in which these supportive or less supportive words made them feel about themselves carried a lot of weight into the next question about their definitions of success and achievement. Overall, success and achievement were viewed as a personal goal and different for everyone: “When you finally achieve / accomplish your goal and you feel proud of yourself” and “Set a goal for yourself and achieve it”. It is also something that varied across cultures: “Varies from person to person” and “Different cultures have different ideas of achievement”. The mention of culture during this section of the focus groups was interesting in that the students were aware that ideas of success and achievement are personal and dependent on the person, how they grew up and “how they experienced their lives”. This idea resonates with Milton Bennett’s idea of ethnocentrism and ethnorelativism in that we all have our own expectations and interpretations of the world around us, so that how we experience the world will be different from the next person. In extension of that idea, the students described how their success “might not seem like a big success to someone (else)” but “for me, it was a big improvement”. Ultimately, students did not disagree with the definitions, but in their experience it wasn’t so much the end result but again, the notice of progress: “It’s not necessarily how much work people into (something) but (that) people see the outcome of it even if you are trying hard”.

Success was also talked about within the realm of respect: “success is mostly getting respect and not wealth or fame”. In a way, the conversation about respect with is reminiscent of the idea that disability can happen to anyone: “Wealth and fame is like, when you lose

those...that can last maybe a couple of years. Loose respect (that feeling) will never go away, it will last your whole life. It's more important to have respect". Ultimately, respect was talked about in terms of cultural sensitivity. Bennett described respect when he talked about acceptance for the values and differences of others. With regard to disability and the definition of success as being individual and personal, it's important to view these differences with respect and value that each individual idea of success is worthy and important.

Culture was again explored in relation to each of their different experiences within their lives, at school, and at home. Students talked about their different experiences with their various disabilities, and this reinforced the notion that disability is an experience unto its own and is certainly an identity with language and experiences that others do not have. One example was when a student talked about, in his experience, the "most derogatory terminology for people with LDs is 'retarded'". He went on to explain that he had been on the receiving end of that word many times in his life. Later, he explained that "students will say 'oh that's retarded' and sometimes that's an OK way to say that. But talking about people or talking directly to someone, 'you're retarded', I think that's very rude". Another student described an experience where he has been called "crippled, or creepy". He mentioned that he looked in the dictionary for the definition of the word "creepy" and it turned out that it "is a word used to describe how a cripple moves around. By definition, I am being creepy when I am just walking into school". One further example about culture and disability was encapsulated in two small statements about experiences with dyslexia, "someone with dyslexia has trouble adapting to a culture that invokes the written word" and "people with dyslexia have to think differently in order to survive". All of these experiences affirm identification and a bond within a culture where others cannot find similarity of experiences in their daily interactions with others and their environment as the

examples have shown. Gilson and Depoy (2000, p. 212) talk about language and culture

similarly:

Language usage becomes a significant role in creating and maintaining a bond among members of a culture and assuring the rapid identification of those who do not belong. Consider the terms used by persons with disabilities such as ‘crop’ or ‘wink’. These terms would be considered derogatory when used by non-disabled people to describe people with disabilities. However, when used by disabled persons among themselves, the terms are not only ‘allowed’, but are often symbols of pride and community.

When asked about words and phrases that, in their experience, were thought of to be the most supportive and least supportive of disability, the responses varied from specific words to generalized phrases that also affirmed much of the previous research of assets and deficits. Students talked about “persistence”, “effort”, “go for it”, “stick with it” and “acknowledgement of the effort” as all being positive and supportive of disability and their determination. Less supportive were non verbal cues such as “stares”, and words like “find a way”, “you’re kidding yourself”, “suck it up”, “too bad for you”, “look at the bright side”, or “not everything is about you”. Further, words like “weird” and “special” and “you belong in a mental institution” were also brought up. Much of these words can be perceived as general language about ability. However, through the perspective of these students and their specific experiences as having a disability label, words like these had deeper significant meaning in their lives. These words imparted in them feelings of insignificance, inability, inferiority, and impacted their sense of identity and ideas of their own personal success and abilities to achieve.

The definition of disability in one student’s own words “roughly translates to no ability at all” in which case, “it’s not a disability, you’re just different” came up as well. Different was then talked about in the sense that “Everyone learns differently”. This also affirms previous research in that disability can be seen as a spectrum of ability, something that affects us all. On

that spectrum is also how individuals learn. Mainstream education, as talked about in earlier sections, typically teaches to logical mathematical thinkers, excluding all other kinds of learners. Learning differently does not mean ‘disability’. Learning differently is just that, different.

Being identified by their teachers as being “different” and therefore having their experiences minimized by others were themes that also arose as being less supportive of disability. One student explained how this is very demeaning:

It is basically giving, without their teacher’s knowledge, [permission for] the students to pick on the other students (who are different). If a teacher announces that you’re different, then that will mean that others can start calling you gimp or retard...that’s where this whole demeaning vocabulary starts...it’s at the acknowledgement for the (other) students.

Similarly, “the idea of when people say demeaning terminology to others, they weren’t actually seeing people for who they are, they see something they associated with something else than what it actually was”. Both of these examples were summed up by another student who said, “it normalizes the idea and stereotypes of being different”. The term “different” was also up for question. One student said that the label “ADHD can be recognized as a legitimate disability. There is a common question, do you prefer learning difference or learning disability. I feel like the term difference belittles the struggle”. In these examples, being labeled as “different” is a negative experience because it minimizes their experiences. At the same time it provides an opportunity for others to minimize them just by being identified as “different”. Both of these ideas are described in Milton Bennett’s Model of Intercultural Sensitivity: minimization and negative stereotypes as a form of denial that students with a disability label can be seen as inferior when compared with the dominant culture group.

One student pointed out that, “Labels come with all of these assumptions. Along with that are lower expectations that are kind of insulting. Because there is a disability, but that’s not

the only thing about them.” Many teachers may be unaware of the difficulties students are going through; labels, as earlier mentioned, can certainly narrow knowledge and understanding of that person and at times only that label can be seen. Edmonds (2012, p. 130) makes the same suggestion:

Many children are erroneously labeled as having behavior problems or being unwilling students, simply because their teachers are unfamiliar with the difficulties these children encounter everyday (as cited by Stordy & Nicholl, 2000; Stansell, 2007).

When the struggles of someone else cannot be understood, despite the attempts of others to understand, inevitably the understanding comes from an ethnocentric perspective. Therefore, language can become one sided. One student, who told the story of growing up with “emotional disturbance,” recalled:

People would always say “calm down.” All right, I know I’m supposed to calm down but I don’t know how to do that. And that’s the problem. 90% of the time people would say “calm down,” and all that would do is get me more upset. Because it’s like, you can’t tell someone who is struggling through physical therapy to just walk.

This illustrates Milton Bennett’s theory of ethnocentrism: where assumption of one’s worldview is central to all reality. Viewing that person who is ‘different’ as being ‘less than’, ‘lazy’, or ‘defiant’ can become the characteristics about them when compared to what is ‘expected’ or what they are exposed to in the ethnocentric world view.

Another reflection of Milton Bennett’s model of Intercultural Sensitivity was when the theme of fear surfaced. One student talked the most about fear in saying, “I think that one thing people without disabilities don’t get, they learn that we’re different and the first reaction is...I’m scared. And I think that’s where a bunch of this negativity comes from. It’s that scared energy.” The same student went on to talk about exposure to differences and learning to understand: “I just think if people understood what we have to go through to make them less scared...that’s why it’s up to people like us to teach them how our brains work...and saying, hey, we’re not

scared of you guys, we just learn differently and there's nothing to be ashamed of." Separation from that which we are unfamiliar with is one of the stages of denial in Milton Bennett's stage of Intercultural Sensitivity. Fear of what is continuously denied and threatening to a dominant way of life can arise from exclusion, and non-exposure. Aptly stated, another student summarized the need to have these dialogues about being different:

If people don't talk about what it's like growing up with a single mom, or growing up poor, or missing a leg or being dyslexic, or what it's like on the other side of the railroad tracks, it's just going to further separate us and make the world smaller. People will be less knowledgeable and people will stick to their own and I don't think that's good.

Lastly, one student talked about the importance of empathy when he said:

I feel like a lot of people just don't get what it's like to be in my shoes or in the shoes of people here at Landmark...to have problems with learning. I always had teachers tell me if I sat down long enough I would get it, but that's just not true. So, I think once people start to learn more I think it (values and language around disability) would be less of a problem.

After analyzing and reviewing the transcriptions from the focus groups, it was clear that the research around disability as a culture of its own with group identities and experiences as separate from socially created norms, is valid and accurate. The students all spoke about their experiences as being a different learner, feeling different, and struggling through school in ways their peers may not have had to deal with. After asking a few simple questions about their experiences as students who identify with a disability, they brought up the topic of culture as something that is experienced differently by everyone. They discussed how their individual experiences impacted how they felt about themselves: their sense of achievement and success and how even those views are different from the views of others, bringing up culture again.

Although the students did not specifically name "assets and deficits" as they spoke, this topic arose from the natural discussion around language that is supportive and less supportive of disability. Some of the language that was brought up focused around the concept of asset versus

deficit thinking, rather than specific words. The theory of assets and deficits was described as building support around individual abilities and a focus on strengths in order to achieve success. Acknowledgement of these strengths was integral to their feelings of achievement, and all of them talked about how individualized achievements can be. The knowledge and affirmation of knowing what one can do in order to build upon already achieved success was very important to all of these students. The ties between what the students talked about and the research on assets and deficits are strong, and serve to illustrate how important encouraging and supportive language around all ability truly is.

Of equal importance and significance to the topic of multiculturalism, and especially to Milton Bennett's Model of Intercultural Sensitivity, the students in the focus groups brought up the concept of respect. Respect was described by the students in their own words as being a path toward greater intercultural understanding. As mentioned, students described respect as a state of being that is more important than success or achievement. Once respect is lost, it can last one's whole life. The understanding here is that respect for and from others is part of how we identify and see ourselves. Ultimately, confidence comes from having and feeling respect. Bennett similarly talks about respect for differences of others within the acceptance stage of intercultural sensitivity: a stage of empathy and understanding of others and their differences.

Fear was another concept from Milton Bennett that was also mentioned in the focus groups. This concept was described as a barrier toward understanding. Many students mentioned that part of their struggle was fear others would see them as "inferior," or fear of others' reactions to what is new and different to them. This fear is also discussed by Milton Bennett as a barrier to intercultural understanding, and can lead to people becoming comfortable in a stage of minimization and denial of differences. Students were able to express as clearly as

Bennett that exposure to differences can lead to understanding more than separation. However, separation is more likely to occur if differences are not first seen as being valid and true for those who truly experience the world in a different way.

Overall, the students expressed views and concepts from their own experiences that strongly connect with the research on the medical and social models of disability. Their experiences at school with several teachers and other students tied into the medical model disability, where fault for their difference was seen within the individual. Meanwhile, the students who identify with a disability view their *environment* as disabling. Experiences that lend to this connection, were hearing teachers, family, and friends using language that is less supportive of their successes and abilities, and classrooms that do not accommodate to varying learning styles in different students. These experiences create feelings of inadequacy and deficiency that the medical model perpetuates. By contrast, they experienced the social model of disability through teachers and family who encouraged them, facilitated identification of current success and assets that were built upon further and individualized for each student.

FINAL THOUGHTS

Mahatma Gandhi once said, “Your beliefs become your thoughts. Your thoughts become your words. Your words become your actions. Your actions become your habits. Your habits become your values. Your values become your destiny.” Upon culminating the integration of the focus group results with research for this capstone on language and its effect on students with disabilities, this one quote in particular sums up much of the findings and points to a starting point that was truly that aim of putting this capstone together: looking at attitudes and awareness around disability.

In their research, Harry and Klingner's thoughts on language proved to be rather similar to Gandhi's ideas on our thoughts becoming our language: "Language in itself is not the problem. What is the problem is the belief system that this language represents" (2007, p. 16). The language we use comes from deeply set ideas and values that have already been in place, and are learned and relearned every generation. Although the focus point of this capstone revolved around the words and phrases used with regard to disability, ultimately, the words are connected to our mindset, perception, and assumptions with regard to disability. In the final focus group, one student summed our meeting by eloquently saying, "I think...when the idea comes first and cultivated over time language is a way to describe them to be true. I think what really comes first is a person's idea then language."

Socially, we inherit our perceptions of those around us by the experiences we live each day. If each day we do not challenge our assumptions, we do not challenge our language or our actions-- which, as Gandhi pointed out, become habits and then values. If this pattern persists, we may never find ourselves in a future where all abilities can work together. Another fitting quote from the final focus group illustrates the creativity that could be, should we open the doorway to disability and look beyond the 'dis':

Like the world, like saying people with dyslexia can't do much is actually making the world smaller. Because think about all the ideas and all the problem solving that could be addressed if you opened up language more and opened up the idea that the dyslexic brain is different than the neurotypical brain. That...doesn't mean it's inferior or superior...it just means (that) in these circumstances it's (going to) be good to be creative.

Can disability present opportunities for learning, understanding, and experiences that otherwise may not be achievable? We cannot know if disability is seen as a barrier rather than an open door to creativity and possibilities.

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APPENDICES

APPENDIX A

Data collection instrument: Questionnaire

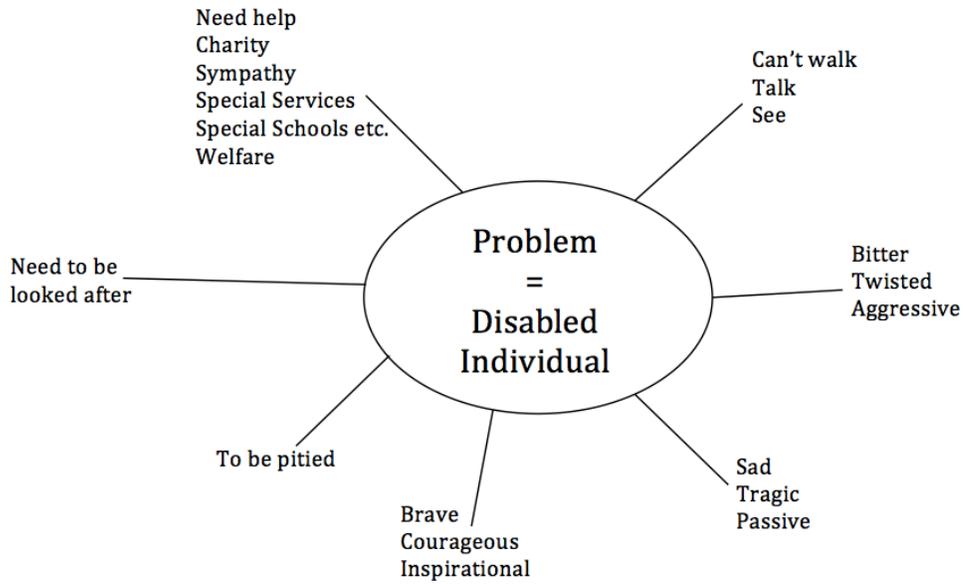
Note: These questions were solely to guide the discussion tasks.

Q. 1.1: Describe an event at school when someone acknowledged you for your strengths or achievements?	Vocally shared by students I will take notes
Q. 1.2: What were some specific words said during that event (Q. 1.1) that made you feel supported?	Written on post it notes and posted on flip chart paper
Q. 1.3: How did those words make you feel about yourself?	Vocally shared by students I will take notes
Q. 2.1: What does success and achievement look like to you?	Vocally shared by students I will take notes
Q. 2.2: How do you feel your definition is different than that of others?	Vocally shared by students I will take notes
Q. 2.3: How did the words we talked about earlier make you feel about your ability to achieve or succeed?	Vocally shared by students I will take notes
Q. 3. 1: With your knowledge and experience, what words or phrases do you believe to be the most supportive and least supportive of ability and disability?	Visually charted by the students
Q. 3.2: Why these words?	Vocally shared by students I will take notes
Q. 4: What does this make you feel about the language we use that could be embraced or avoided around ability and disability?	Vocally shared by students I will take notes
Q. 5: What is one thing that you are thinking about or will do differently after this session on language?	Vocally shared by students This is a closing take away question and not something I will be noting

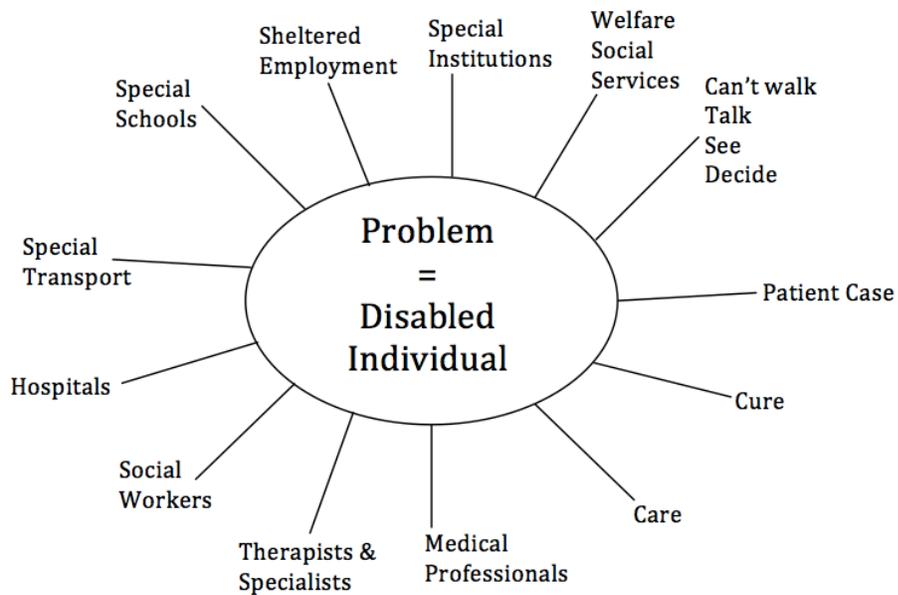
APPENDIX B

Three Models of Disability

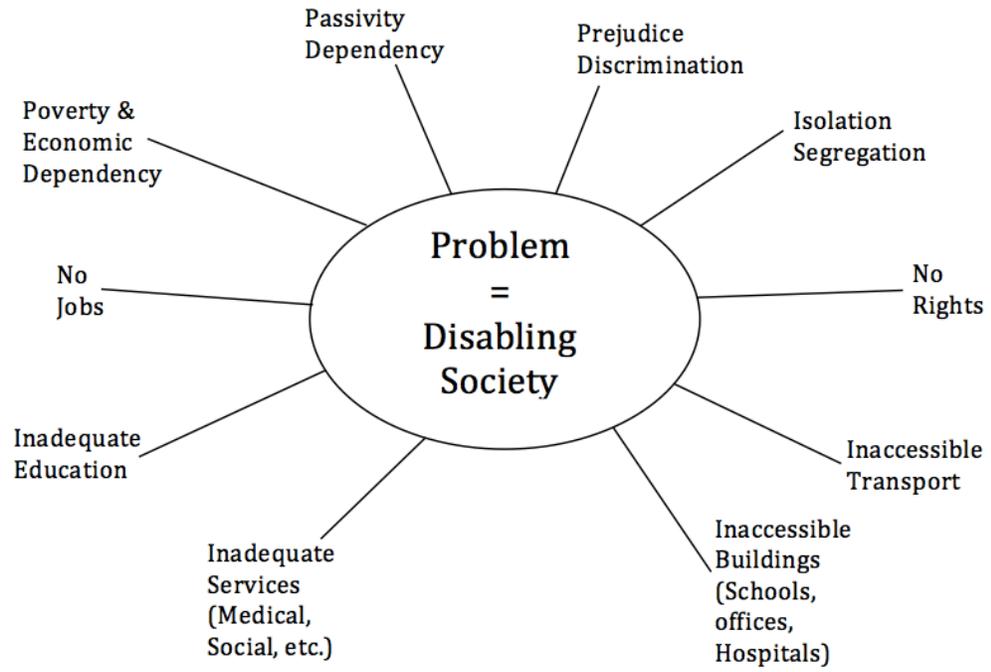
The Charitable Model of Disability



The Medical Model of Disability



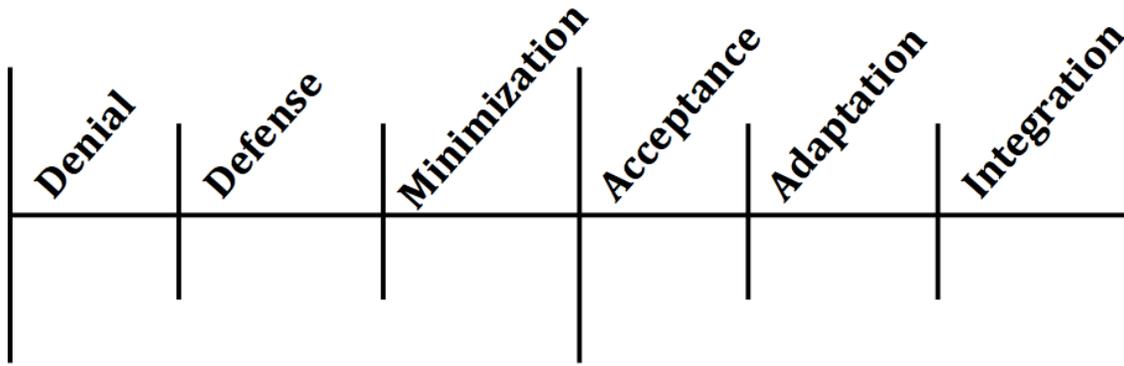
The Social Model of Disability



APPENDIX C

Developmental Model of Intercultural Sensitivity – Milton Bennett

Experience of Difference →



Ethnocentric Stages

Ethnorelative Stages

Milton Bennett