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USING ANTHROPOLOGICAL PERSPECTIVES TO INTEGRATE THE  
SOCIAL AND MEDICAL MODELS OF DISABILITY

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USING ANTHROPOLOGICAL PERSPECTIVES TO INTEGRATE THE  
SOCIAL AND MEDICAL MODELS OF DISABILITY

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## DEDICATION

To Joshua, whose incredible heart stands as my original inspiration.

Mom, for reminding me that I could always pull over to the side of the road, or even play hooky and bake cookies. Jess, for being my toes and biggest fan. Ande, for ensuring I had clean clothes and food. Dad, whose endless dedication and insight makes me sorry to report, six years later, I still know nothing about the stars.

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## ABSTRACT

The medical model of disability views the challenges and solutions to disability via medical terms. Within the social model of disability (SMD), impairment is the physical condition specific to a person, whereas disability is produced by society's reaction to impairments, which leads to exclusion from full participation in society and ultimately oppression for people with impairments (Hunt 1975). Despite their different perspectives, an integration of these two models provides a holistic representation of disability within the United States. The unique experiences people with disabilities have with language ideologies and technology are two aspects of life anthropological perspectives can be used to investigate in relation to these two models of disability. The potential for both limitations and sources of improvement are found within the social and medical aspects of disability.

## INTRODUCTION

In kindergarten one day my brother, Joshua, was asked to say the word “red” by a classroom aid. Joshua was diagnosed with cerebral palsy at birth due to an accident during the delivery and uses a wheelchair for mobility and a speech device, called a Dynavox, to communicate. The classroom aid grew disgruntled by my brother’s refusal to try to pronounce the word and then proceeded to say the word slowly, enunciating each letter repeatedly. While she was doing this, my brother was turning on his Dynavox, which takes a few minutes to start up. He then proceeded to type out “red” about ten times; I like to think it was the most smart aleck a computer-generated voice has ever sounded. This is just one of many incidents throughout Joshua’s education where he had the adaptive technology necessary, but that did not ensure it would be utilized to achieve inclusion in the classroom. This example encapsulates the importance of a broad understanding of disability. A view of disability that focused heavily on the medical and technological approaches necessary for people with disabilities would not be well equipped to foresee such a complication. However, a view that included a focus on the importance of society’s response toward disability would be better suited for these types of complex situations that arise.

The social model of disability's (SMD) primary goal is the full inclusion of people with impairments into society through the eradication of societal responses that act to exclude them (Shakespeare 2006). The many ways anthropology stands to offer insights about disability within the United States while engaging the SMD are outlined in this thesis by considering the medicalization of disability, the language surrounding disability, and cross-cultural examples of the treatment toward people with disabilities. Also, a look at the policies in place to promote social inclusion and the current state of affairs for people with disabilities are considered, and suggestions are made for how to achieve full citizenship and more meaningful inclusion. I argue that anthropology is well positioned to illustrate the importance of the SMD within a medical model due to the ability anthropology has to focus on the social and environmental factors of disability; and that through this illustration a comprehensive understanding of exclusion and future solutions for inclusion can be found.



## CHAPTER 1: SOCIAL AND MEDICAL MODELS

Examining the way practices shift over time provides examples that stand to challenge the status quo. The process of medicalization is one such practice that can be inspected to show the values and assumptions held by a society. A comprehensive discussion about the medicalization of disability will provide a way to discuss aspects of disability that are often hidden. On the one hand, the improvements to people's lives that have been made by medical discoveries for new treatments and technologies are due, in large part, to the medicalized status of disability. On the other hand, the hyper-medicalization of disability can be seen to maintain an innate distance between people with and without disabilities. This distance allows for environmental factors to never be identified as at least partially responsible for creating the conditions in which people with disability are routinely excluded from many aspects of society, as outlined by the SMD.

Arguments will be presented that highlight how people can be culturally influenced to consider a condition as primarily a medical issue rather than a social one, which then limits the way treatment is approached. Considering a combined approach to the medical and social model of disability, discussed later in this chapter, is influential for

potential health outcomes through the expansion of treatment approaches.

## **MEDICAL MODEL OF DISABILITY**

Medicalization has been defined in different ways throughout various fields of social science. “All problems that come to be defined in medical terms” will be the definition utilized within this paper (Conrad 1992). The reaction this process generates often depends on the particular aspect of human life that is being medicalized. Some are more widely accepted as strictly medical issues, while others are viewed as more of a social issue depending on the values and beliefs held within a society. Factors influencing where this line is drawn within medicalization has been discussed at length within medical anthropology. Historically, new technology aids in the move towards medicalization because it creates a divide between the patient’s account of their health and the observable truth of science (Lock 2004). Only professionals were able to see this “truth” due to advances in technology such as stethoscopes or X-ray machines (Lock 2004).

Often, when the medicalization of certain areas of life comes into question, the solution presented is demedicalization. One successful example of this is the demedicalization of homosexuality. Before it was demedicalized in 1987, electric shock therapy, aversive conditioning, lobotomy, and castration were all treatments prescribed with the goal of

curing individuals of their homosexuality (American Psychiatric Association 1987; Conrad 2008). A relatively short period of time later, there is considerable agreement that demedicalization of homosexuality was the correct choice, and we can observe how the quality of life has increased for individuals in direct connection to this shift. As a result, it often is used in support for the demedicalization of society in general (Conrad 2008). Other aspects of society that have become medicalized, however, might not be as clear-cut. To come to a conclusion regarding the appropriateness of the medicalization of disability, a thorough understanding of disability, as well as the advantages and disadvantages of medicalization need to be investigated.

### **Disease Causality**

One positive aspect of medicalization has been presented within the literature is the displacement of responsibility and stigma that happens as a result of moving a problem into the medical realm. While this has been observed to a certain extent, it is a complex phenomenon important to explore. The idea is based on the assumption that once a problem becomes defined through medical terms, it no longer incurs religious or legal scrutiny, therefore circumventing the punishment and responsibility that would go along with such scrutiny (Zola 1972). However, the reality of medicalization is that it does not always follow this prescribed path. Moral judgments often still dwell below the surface. One

way this moral judgment becomes articulated within a medicalized aspect of life is how it is used to rationalize why one person developed a certain condition over someone else (Zola 1972).

The results of medicalization differ in terms of the condition that is being medicalized as well as within the condition itself. One aspect of medical knowledge production that contributes to the array of effects medicalization can have on the experiences is due to the range by which disease causality is understood. Even when aspects of human life are understood within a medical framework, differing ideas of disease causality complete for influence over how risk and cures are negotiated. Sylvia Tesh outlines three theories of disease causality that all exist alongside each other within a current understanding of health and illness (Tesh 1988). She describes how three different theories, germ, lifestyle, and environmental, all stand to influence how risk and responsibility are allocated from a single causative agent to individual action to government intervention (Tesh 1988). Understanding that there exist, simultaneously, radically different understandings of health and disease helps to illuminate how the medicalization of a condition does not translate into a clear-cut displacement of responsibility from the individual. It also helps to point out how solutions to medical problems can exist outside of the medical lens, which would remain overlooked within a strictly medicalized approach.

## **Advantages of Medicalization**

Research and funding are available and directed toward finding solutions to problems facing people with disabilities when disability is considered through a medical lens (Conrad 1992). Also, this method allows for degenerative and chronic impairments to be given individualized medical attention.

A strict adherence to the social model of disability would ignore the life changing benefits the medical model has to offer (Shakespeare and Watson 2001). For example, cerebral palsy (CP) and multiple sclerosis (MS) can both result in the necessity of a wheelchair, which would mean both individuals would be invested in the social aspects of their disability as it will affect where accessible entrances to buildings are, public transportation, etc. However, there is ongoing medical attention necessary for MS as symptoms progress and/or change, which illustrates that a strict view of the social aspects of disability misses the mark. Conditions that are more "fixed" in their symptoms, meaning their symptoms do not typically progress and/or change due to the nature of the condition, as cases of CP often are, might not lead to the same view of where the distinction between the medical and social roles in disability rests (Shakespeare and Watson 2001).

In addition to the medicine and surgeries that have been developed to save lives, categorizing disabilities within a medical model

brings them under the purview of health care (Kasnitz and Shuttleworth 1999). As a result, there is funding available for adaptive technology, physical and occupational therapy through health insurance. Technology represents a field that has the potential to bridge the gap between what personal ability and environmental demand. Under a medical model of disability, technology becomes approved and paid for by medical insurance as it falls under the umbrella of a medical necessity (Litvak and Enders 2001). Adaptive technology has been found to mediate sources of stress for both the individual with a disability and caregivers because it reduces the overall hours of help needed, which increases the person's sense control over aspects of their own life (Verbrugge and Jette 1997 and Hoenig et al. 2003). There have also been efforts to utilize technology within classroom settings in ways that would not only increase the learning potential for children with disabilities but also create a more even playing field for them to interact with their peers in an inclusive environment (Pearson and Bailey 2007). However, the development of adaptive technology is only the first step in assuring that the benefits medicalization has to offer disability translates into real world improvements. If a society is not open to accepting alternative methods of communication and mobility, these solutions do not translate into inclusion for individuals with disabilities; a topic that will be explored further in Chapter 4.

## **Disadvantages of Medicalization**

One disadvantage of medicalization is that it dichotomizes aspects of human life, that is to say, it distinguishes sickness from health and works to keep them separate (Rose 1994). I argue this result of the medicalization of disability has influenced the way secondary illnesses associated with disability are viewed. If people with disabilities occupy a "sickness" category within the minds of the medical community and society at large, it might be that additional illnesses act as an affirmation of this dichotomy between illness and health, rather than raise red flags to the treatment of people with disabilities. In an attempt to expose this disadvantage within the medicalization of disability, I will consider some of these secondary illnesses and the possible red flags within society.

Currently, people with disabilities have a higher risk for a range of secondary health conditions ("Related Conditions" 2016). Some of these conditions, such as fatigue and pain, are typically understood to result from a chronic overuse of certain muscles as compensation for a particular disability (Ehde et al. 2003; Yorkston et al. 2010). However, other secondary conditions such as depression, stress, and obesity are not exclusively biologically determined, but rather are also influenced by social factors. Research has found that factors such as stigma, social exclusion, and insurance cost are connected to the psychological distress

experienced by people with a disability (Pearlin et al. 1981, Ormel et al. 1997, and Alang et al. 2014).

## **Stigma**

When a person deviates from a socially agreed upon definition of normal, stigma often results (Goffman 1965). Within this definition of stigma, if an individual is capable of fulfilling what is valued within a given society despite their physical impairment, they can avoid the extremes of stigmatization without the implementation of social interventions. Therefore, the overall values and worldview a society shares can determine the response to disability, which in part explains the varied nature of social resources that can act to increase or decrease challenges for the inclusion (Verbruggle and Jette 1994).

There are many reasons people become stigmatized, however, for people with physical impairments it is a source of social stress that is difficult to avoid due to the visible nature of their "difference" (Page 1984). People can become aware of the stigma placed on them by either self-reflection on the values of a culture they are part of, or via explicit treatment from the public (Page 1984: 9–10). The recognition of one's stigmatization often leads to diminished self-esteem and feelings of control over life and choices, which can contribute to the onset of depression (Corrigan and Watson 2002).



Social exclusion due to stigma can be seen to take different forms with various consequences. A study which observed people's behavior towards a physically disabled individual found people's behavior and speech to be extremely controlled and inauthentic (Kleck et al. 1999). Movement and gestures were reduced, people catered their opinions to reflect ones they anticipated the person with a disability to have, and they described their impression of the person with a disability in a hyper-positive manner. While this description of behavior is not likely to be judged as disrespectful by everyday onlookers, it still represents an insidious fact of life for many people living with a disability because it represents exclusion from "normal" social interaction (Page 1984 and Kleck et al. 1999).

However, when individuals with disabilities pursue social inclusion the exclusionary behavioral responses become more overt (Page 1984). The hyper-nice behavior often alters into resentment towards individuals with disabilities who presume this right of inclusion. In one example of this, nearly seven hundred people were at a dance hall when a group of people using wheelchairs arrived and pursued a place on the dance floor (Berk 1976). Within half an hour, over two hundred and fifty (~36%) of the original people left the room, overheard using slurs such as "those misfits" within conversations articulating the sentiment that it was inappropriate for them to have pursued that level of inclusion at a dance.

Social exclusion can have profound consequences for health. During events of social exclusion, the brain has been observed to react in a similar manner to when it experiences actual physical pain (Eisenberger et al. 2003). Additionally, another study found that people who had previously experienced a life event where they had been intentionally rejected became depressed close to three times faster than people without a history of social rejection (Slavick et al. 2009). Stigma and social exclusion can be understood as ways that societal reaction to disability contributes to the production of health risks, which acts to integrate the natures of the social and medical model of disability (Oliver 1990).

The reality is that the medical professionals who are responsible for providing the assistance often conceptually restricted to the medical model live in the same social environment as everyone else. Medical professionals do not exist inside a vacuum. A study was conducted looking at perceptions of quality of life after a severe spinal cord injury that compared views of emergency medical staff to those of people with spinal cord injuries (Gerhart et al. 1994). 83% of the medical professionals judged the quality of life to be lower, whereas only 14% of people with these injuries judged their quality of life to be lower. Perhaps even more staggering, only 18% of the medical professionals thought they would be happy to be alive after such an injury; compared to the

92% of people who had sustained such an injury had reported. These medical professionals are the ones qualified to advise politicians on questions of health care policy, resource allocation, and treatment recommendations (Basnett 2001). This reality supports the rationale that the SMD and medical model are not mutually exclusive.

### **Moving Beyond the Dichotomy**

Neither the view of disability via purely medicalized terms or social ones seem to capture the complex dynamics at play accurately. While adaptive technology exists as a result of medicalization, if it does not fulfill what is valued within a given society it will not translate into the reduction of stigma and, by extension, social exclusion.

The medicalization of society is equally a consequence of medicine's potential as it is of society's wish for the medicine to use that potential (Zola 1972). As a result, while medical approaches that become available once disability is covered under health care can move towards closing the gap between physical ability and environmental demand, it still relies on societies willingness to accommodate demands created by technology and the person using them. Every step of the way it requires understanding and acceptance. All of these factors make clear the importance of not only technology but also societal values working towards inclusion. Challenging the social structure within society that facilitates these factors would not alter the underlining biomedical reality

of disability; it would, however, act as a way to close the gap.

Understanding now the importance of this interplay, a unique example of social inclusion will be presented throughout this paper and then analyzed through both medical and social lenses.

## **SOCIAL MODEL OF DISABILITY**

The SMD has been incorporated into many different fields of study interested in disability and therefore has taken on a range of meanings within each context. The origin of this model was in Britain during the 1970's due to the formation of the Union of Physically Impaired Against Segregation (UPIAS) (Shakespeare 2006). The UPIAS was a group formed by people with disabilities, including Paul Hunt and Vic Finkelstein, were disillusioned by both the goals and results of the disability organizations of the time (Shakespeare 2006). The UPIAS outlined impairment and disability definitions that became the crux of what Michael Oliver later coins as the "social model of disability" (Shakespeare and Watson 2001:549). Within SMD, impairment is the physical condition specific to a person, whereas disability is produced by society's reaction to impairments, which leads to exclusion from full participation in society and ultimately oppression for people with impairments (Hunt 1975). Within the United States, this model is sometimes referred to as the "minority group" model of disability, where the oppression of people with impairment faced is thought of as having similar experiences to what

groups oppressed due to factors such as ethnicity, gender, or sexuality (Williams 2001).

A medical model of disability is one that attributes the “problem” of disability to the individual, explaining that their challenges are due to physical impairment or psychological distress (Williams 2001).

Alternatively, the SMD explains that the problem rests in society's reaction to disability and lack of accommodations. This failure results in the prevalence of systematic discrimination of individuals with disabilities throughout society. The SMD allows for the social environment to be a unit of measure within disability studies which opens up space for anthropology to engage with this discussion in a nuanced way (Battles 2011). Anthropological perspectives are positioned to provide compromises to some of the criticisms the SMD has garnered over the last forty years.

### **Disadvantages of the Social Model**

The SMD has undergone scrutiny for being too rigid to encompass the broad range of complexity facing disability (Shakespeare 2006). One such aspect of the rigidity of the model is its erasure of individual experiences in its attempt to categorize society as the issue (Battles 2011). As a result of focusing on society rather than impairment, the SMD suggests impairment itself does not propose a challenge to people lives

(Shakespeare 2006). For this aspect of the SMD to apply to people's situation only works for certain types of impairments. It is not realistic to view society as their only barrier for people with chronic or degenerative illnesses requiring prolonged medical attention (Williams 1999). In this way, a shift away from focusing on the individual lived experience results in a model that only partially explains challenges facing people with disabilities.

### **Advantages of the Social Model**

While the departure from the individual is the major critique of the SMD, it is complex because it is also an aspect of the model that some groups consider one of its most profound strengths. A researcher interviewed 33 people with visible physical disabilities and found that people described a change in their self-image when considering disability within a societal framework rather than an individual medical condition (Phillips 1990). This outcome is consistent with the original goals of the creators of the SMD who understood the political implications of disease causality. The following chapter will discuss the importance of disease causality in more detail. However, briefly stated, the members of the UPIAS understood that shifting the responsibility for the disadvantages experienced by people with disabilities from biological to societal would result in the blame being transferred from the innate lacking of the individual with an impairment to society's failure to provide an inclusive

environment (Amundson 2000).

The need for a reexamination of the causal factors of disability comes from the interdisciplinary reality of society (Wasserman 2001). If the social activist arguing for the reduction of oppression for people with disabilities could be the same person who has the medical and technological skill set to create adaptive equipment, as well as the political power and city-planning expertise to create an ideal built environment, then disability could be conceptualized as purely social. In reality, those five skill sets mentioned alone require years of considerably different educational backgrounds that encourage different worldviews and priorities. Even if all social stigma surrounding impairment were removed, without biomedical experts, the comfort and even survival of people with impairments would still be a barrier to experiencing life similarly to those without impairments. Similarly, though, even if an idealistic built environment was achieved and people with impairments had the adaptive technology they needed for communication, health, and mobility, it would fall short of translating into inclusion without a societal acceptance of those type of adaptations.

These views of causality do not need to be treated as mutually exclusive. David Wasserman suggests that the rigid view of causation by the SMD is a deliberate over correction to ensure moral and political responsibility is taken up by society (Wasserman 2001). The fear is that if

any allowance is made for how biological realities are negatively impacting people with disabilities, it will open the door to a complete understanding of disability as something a person must suffer through alone.

The integration of the social and medical models are already taking place in the everyday lives of people impacted by disability. In a study looking at African American families that include children with special needs, researchers found that parents would conceptualize inside and outside of a general category depending on the specific situation (Jacobs et al. 2010). At times parents reject their children being given treatment plans based off of statistics of what worked for other patients in a “similar” situation. In these instances, parents insist on an individual view of their child informed by factors outside of the medical model. The specifics of their family, ethnicity, economic, education, and individual character all motivate the parent to reject their child being discussed as a number within a larger subset (Jacobs et al. 2010). This example uniquely acts to turn the advantages and disadvantages of these two models on their heads.

While society is responsible for aspects of disablement, it does not act on impairments blindly or equally. In this way, the individual's specific situation within society can be investigated to represent better their unique situation to understand how multiple social forces are at play. I



argue that this slippage between the two models already takes place by the people living among disability, as articulated by the example of African American parents juggling their child's individuality while at other times placing them within the collective. It is important that future research reflects this occasionally messy integration and allows the models to mutually benefit from each other rather than framing them as mutually exclusive.

## **Conclusion**

Ultimately, the medicalization of society is as much a result of medicine's potentials it is of society's wish for the medicine to use that potential (Zola 1972). Understanding that medicalization is not the result of a purely biological fact, but rather societies reaction to certain aspects of life allows for room to consider both the medical model as well as the SMD. An examination of the advantages and disadvantages of the medicalization of disability makes it clear that only a nuanced solution combining both the medical understanding of disability with a SMD could create a higher quality of life for individuals with disabilities. It would be impossible to deny the advantages medical attention has afforded individuals with disabilities. However, adaptive technology has to not only be medically beneficial but also has to be socially accepted for the gap between environmental demand and individual ability to begin to close. As a result, the medicalization of disability is appropriate, but it needs to

be opened up to allow for sickness and health within the category of disability as well as distribute responsibility equally between a medical intervention and social behaviors.

As anthropology moves away from limiting its engagement of disability studies to medical anthropology, a compromise can be observed that will be proposed to capitalize on the advantages of both a medical and social model of disability (Kasnitz and Shuttleworth 2001). An examination of the language surrounding disability will also offer insights into ways to mitigate the deindividualizing aspect of the SMD while still retaining its power to shake off the stigma of disability. Additionally, a look at cross-cultural aspects of disability offers insight into what degree disabilities are the result of medical rather than societal factors. All of these points of examination will be outlined in the following chapters and act as examples of how anthropology is capable of engaging and possibly improving the two models.

A quick point of clarification on terminology, within a strict social model of disability, people with impairments are referred to as "disabled people" (Shakespeare 2006). This brings up a point of contention within disability studies: people first language. Phrases like "people with disabilities" or an "individual with a disability" are seen by a strict adherence to the SMD to be perpetuating the medical model of disability. Since disability in those phrases is referred to like something a person

can "have" rather than something that is placed on them by society (Shakespeare 2006). As this paper is an attempt to bridge the gap between strictly social and medical models, taking the best of both models, people first language will be adopted even while discussing the merits of the SMD for reasons that will be further discussed in chapter three.

## CHAPTER 2: DISABILITY AND MEANING

“Disability only exists in reference to ability” (Kasnitz and Shuttleworth 1999: 8). As such, conceptualizations of disability relies on a specific culture’s understanding of ability. Disability can be the result of an accident or illness, chronic or acute, visible or invisible. The pivotal aspect of disability is it is an impairment treated as a disability within its own cultural context (Kasnitz and Shuttleworth 1999). This definition relies on the knowledge specific to a place and time to gain insight into what is considered a "disability." Within the contexts of this paper, unless otherwise specifically stated, "disability" will be in reference to visible physical impairments within the United States. These are certainly not the only type of disability within the United States, however, for the purposes of this paper, this will be the focus.

### **Anthropology and Disability**

Denaturalizing the way aspects of life are in a specific time and place by citing examples counter to the accepted norm is an ability that has been employed by anthropologists across subfield distinctions to challenge aspects of ethnocentrism, xenophobia, sexism, racism, and homophobia, to name a few. Similar to many of these challenges, disability is experienced differently depending on the specific political, social, and economic realities facing an individual (Ginsburg and Rapp

2013). However, disability is a unique case when considered along side those other categories because it is one in which any member of society can transition into through illness, injury, or aging (Ginsburg and Rapp 2013). Considering this potential to impact any and every human, it is surprising that disability has not been studied more within anthropology (Kasnitz and Shuttleworth 2001 and Staples and Mehrotra 2016).

Ruth Benedict is credited as one of the first people within American anthropology to shed light on disability (Staples and Mehrotra 2016). She studied cross-cultural perceptions of epilepsy where she compared cultures that considered it as a disability to ones that saw it as a special ability (Benedict 1934 and Staples and Mehrotra 2016). Subsequently, Margaret Mead urged the study of people with disabilities within anthropology by claiming that Americans cannot be accurately portrayed by leaving out an entire group (Mead 1953 and Staples and Mehrotra 2016). However, until recently, disability studies within anthropology has been considered a topic for medical and applied anthropology exclusively (Rapp and Ginsburg 2013). As a result, it is not typically fully integrated into the range of subfields within anthropology the way other factors have been, such as gender, ethnicity, or sexuality, have been. Calls to expand the theoretical perspectives engaging disability studies within anthropology have been made though and have resulted in a broadening

of ethnographic studies (Kasnitz and Shuttleworth 2001, Rapp and Ginsburg 2013, Staples and Mehrotra 2016).

Disability impacts and is impacted by every area of life: family, community, religion, medical, and technological, to name a few (Rapp and Ginsburg 2013:54). As such, this thesis will utilize the recently suggested expansion of theoretical frameworks, as stated previously, by considering medical, linguistic, and sociocultural anthropological perspectives to try to integrate the SMD within a medical model framework.

### **Anthropological Approaches to Disability**

Anthropological methods are key to considering the complex role disability holds within society. To gain an anthropological perspective of disability, ethnographic studies are conducted to understand specific experiences facing people with disabilities as well as gain cross-cultural examples of the range in which disability can exist. A large part of the anthropological research that has been conducted has been self-reflective by anthropologists who have a disability themselves or are closely related to someone who has one (Kasnitz and Shuttleworth 2001). However, as disability studies become more fully integrated into anthropology, there is a broader range of perspectives possible.

Disability can happen at any point in a person's life and because of this, it can take on a range of meanings depending on the conditions influencing their social world prior to their disability. Conceptually there has been debate on whether to consider people with disabilities a minority group, with some anthropologists cautioning lumping a diverse set of experiences into a single category (Reid-Cunningham 2009). There is an often both distinct and at times overlapping definition between physical and mental impairment (Reid-Cunningham 2009). The Americans with Disability Act (ADA, 1990) makes a distinction between physical or mental impairment in its definition; yet many of the resources for people with disabilities are still lumped into the category of "disability" (Estroff 1985: 167). Estroff describes sheltered workshops where people with wide ranging impairments are sent to do menial, low-paying work and as a result, "mental" health problems become "health" problems in general, and the line becomes blurred between different "types" of disability (Estroff 1985: 167).

This presents an interesting challenge to how disability resources should be handled. While there is often a distinction between types of disabilities in name, in actual practice, whatever categories that have been created become lumped together. If there was not the distinction from the onset, perhaps there would not be the assumption that one

person's disability is comparable to another's; wherein maintained individuality would combat shared stigma.

### **Contemporary Cross-Cultural Examples of Impairment and Disability**

The Diagnostic Statistical Manual of Mental Disorders (5th ed.) (DSM-V) acknowledges the existence of cultural concepts of distress (American Psychiatric Association 2013). Three concepts are presented for the assessment of these disorders: syndromes, idioms, and explanations (American Psychiatric Association 2013:758). Cultural syndromes are a grouping of symptoms that co-occur within individuals of similar cultural grouping. Idioms of distress can be understood as culturally shaped ways of expressing distress, which lead to the use of similar words like "depression" or "nerves" in dissimilar ways depending on the culture. Cultural explanations are a way of understanding for the method of causation for symptoms, illness, and distress (American Psychiatric Association 2013:758). All of these factors work together to form a culturally specific way of viewing and treating illness, which illustrates the role society plays in health (Kasnitz and Shuttleworth 1999).

As previously stated, the overall values and worldview shared by a society has the ability to determine the response to disability, which in part provides an explanation for the varied nature of social resources that can act to increase or decrease burden for members of the society with a



disability (Verbrugge and Jette 1994). Patrick Devlieger observed the Songye society and their response to impairment of the upper and lower limbs. He stated that their cultural values were such that impairment did not just reflect on the individual, but was indicative of former actions by the family and society members (Devlieger 1995). Devlieger cites this worldview as the reason individuals with impairments did not experience extreme stigma, as they are still viewed as compliant to valued norms. Instead, he observed that individuals with these impairments were given the level of work they were capable of completing, such as taking care of the house and children while parents were away.

### **Liminality**

Society is made up of culturally approved positions (Turner 1969 and Willett and Deegan 2001). Liminality is the movement outside of one of these approved positions (Turner 1969). People with disabilities have been conceptualized as occupying this liminal state; neither completely ill or well, included or excluded (Murphy et al. 1988). This is an interesting perspective to view disability though because all humans exist on a gradient of ability and health. Today, a person utilizing corrective lenses and incapable of completing a marathon would not be considered to have a disability, yet they occupy a different space of ability than marathon runner without lenses. With this in mind, I would add to the idea of disability as a liminal state that these "culturally approved positions" are

not static, identical positions. Rather there are culturally approved ranges, which can come to be defined differently over time.

Through this liminal state, people with disabilities are allowed insight into the building blocks of a society (Turner 1969 and Willett and Deegan 2001). They have to learn what is required from viable members of society as they attempt to reenter an accepted structure. Cheryl Mattingly discusses African American families being thrown into this state of liminality inside the hospital when they receive a cancer diagnosis for a child (Mattingly 2010). This journey to navigate this new state takes on a range of meaning on a personal, interpersonal, and structural level. Cultural identities that parents had previously learned to navigate such as race, class, or gender gain a heightened meaning in these instances because it poses a challenge to their balance (Mattingly 2010).

## **Conclusion**

Drawing attention to disparate views towards disability and disease observable via the comparison of past and cross-cultural populations helps support a consideration of the influence society has on creating categories of disability. Broadening the scope to consider how societal factors interact with biological factors allows for consideration of alternatives observable in cross-cultural examples, which ultimately acts to challenge beliefs of the innateness of disability.

## CHAPTER 3: LANGUAGE IDEOLOGIES

Many concepts surrounding disability have been produced within the United States by incorporating concepts originally considering gender and race. The damaging way language is used to perpetuate racism can similarly be understood within the context of disability. The language used within policy during the early to mid-twentieth century justify racially based segregation is being used today for disability. Additionally, many disability activists utilize humor in ways similarly described within ethnographies of race. Adaptive technologies also introduce a unique challenge to the way people with disabilities are perceived. To highlight and examine these issues, concepts from medical anthropology will be included to illustrate the language surrounding disability.

### **Saussure and Person First Language**

Rose Galvin proposes a way to link Saussurean linguistics with Foucault's work on discourse in order to consider how language stigmatizes and has the power to reverse the stigma (Galvin 2003). Saussure developed semiotics, which can be understood as the science of signs where the signified represents the concept, the signifier represents the sound pattern alone, and the sign represents the link between the two (Saussure 2011). It is an important distinction that the sign unites a concept and a sound pattern, not a name and a thing (Gavin

2003). When a word is replaced, it does not alter the concept/signified, just the sound pattern/signifier used to denote it. This helps to explain how words seem to go through a cycle of being socially acceptable to only years later be considered "politically incorrect." It is not possible to lose the negative subtext of a concept simply by replacing the sound pattern used to convey it. However, the connection between the signifier/sound pattern and signified/concept can justify the importance of person first language (Galvin 2003). When the signifier/sound pattern "disability" is replaced with the signified/concept "disabled," a person becomes the concept. As a result, a person becomes reduced down to one aspect of their life.

## **Metaphor**

Metaphors work by hiding parts of a concept and focusing/highlighting others (Lakoff and Johnson 2008). They work by taking cultural or physical experiences and comparing them to another. Hill discusses the use of metaphors and points out that "immigrants are animals" is a pervasive metaphor used and be seen in phrases like "catch-and-release" when talking about immigration policies and using a "small-varmint gun" on immigrants (Hill 2009). Understanding that metaphors are easily taken for granted within speech, this metaphor works at a level invisible to people "inside the system" to such a degree

someone will not be immediately called out as racist. All the while, it is left unchecked to reinforce this deep seeded mental linkage between immigrants and animals. There are similar metaphors present within the culture for disability. "Disability is lesser" is one frequently used by appropriating medical terms for conditions that people with disabilities experience. This metaphor is what makes terms previously accepted within a medical setting no longer appropriate such as "retard" or "lame." These metaphors work as insults because of the negative view that is given to the concept of disability (Galvin 2003). As discussed previously, this demonstrates how when a new word (pattern/signifier) is presented for a certain disability (concept/signified) there is only a limited amount of time before that new word gains a negative connotation, because it has done nothing to alter the concept, which is what continues to be used in metaphors to represent "the lesser".

## **Discourse**

Foucault used discourse to mean the different ways knowledge gets organized through speech, semiotic resources, and practices (Duranti 2009: 12). Hill adds to this definition the aspects of communication that are not spoken such as the silences, inferences, and clues that work to transfer meaning (Hill 2009). It is important to understand that knowledge is controllable through discourse because the

way it gets relayed over time and space is susceptible to alterations, as demonstrated in the previous section concerning semiotics (Gavin 2003 and Duranti 2009). This is a relevant consideration when looking at disability because it, in part, explains how people can lose control of their narratives and how those narratives can have a pervasive role in their lives (Galvin 2003). Discourse can be seen within linguistic ideology as a way to produce influence within people's lives.

### **Language Ideology**

Language ideology is the conceptions and employment of language within a social context (Duranti 2009). Hill states that language ideologies shape and limit discourse and as a result, they also shape and limit other ideologies, such as disability (Hill 2009).

Some language ideologies make discrimination and stereotyping highly visible, such as performative ideology (Hill 2009). It is concerned with how language makes people feel and views language as active with the ability to wound or comfort. Hill explains that this ideology is used to support the criminalization of "hate speech" as language used to wound and capable of assault rather than expressing the truth. This ideology is based on Austin's observation that all language is performative to some degree (Austin 1975). The words become performative because the speaker means something by them and that causes a reaction. Combined

with the referential power of indexicality, gender, ethnic, and disability identities can be constructed by a speaker (Duranti 2009: 19).

Disability theorists have considered Judith Butler's work on the performative nature of gender and found it to be extremely applicable to the creation of disability identity (Samuels 2003 and Butler 2011). Butler observes that gender is performative because it is the performance of gender that creates the identity of gender rather than the universal presence of gender before such a performance (Butler 2011). Due to the self-creating nature of this performance, disability can be seen as socially constructed and then reaffirmed through performance (Samuels 2003 and Butler 2011). As a result, language surrounding disability has the power to define and influence disability identity.

While some language ideologies are overt with discrimination and stereotyping, others are much more insidious with their methods. One of these ideologies is personalism, which is the belief that the important part of language is the speaker's intention (Hill 2009). People discussing disability use this ideology ubiquitously. Under the protection of this ideology, there is no need to become informed about the slurs, jokes, labels, or any aspect of language that might be extremely harmful to a person with a disability.

Within a personalism ideology, gaffes represent a way to excuse a speaker for a discriminatory slur by excusing it as a "slip" or a joke (Hill 2003). Despite the fact that the joke or slur might have been hurtful to the listener if the speaker claims their intent was not to hurt, they expect to be excused. Further, if the listener does confront the speaker for their slur or joke, they can be met with frustration or hostility for taking the joke too seriously. Hill presents that this ideology allows for "social alexithymia", which is inattention toward sensitivities and even outright rejection for the authenticity of certain feelings (Hill 2009:96). Justifications like, "that is not what I meant", "you should understand where I am coming from", or "I was just kidding" all provide a pass to the speaker while offering no solution or opportunity to the listener to feel heard or understood. Additionally, there is no requirement to prove initial intent and as a result (Hill 2009). As a result, there is no onus placed on the speaker to ensure their statement even sounds like a joke. Instead, the speaker can use a known slur, and it is not until they are challenged, which they often are not because of social alexithymia, that they have to explain it was a joke. This cycle that is created and protected by personalism ideology can act as a way to silence the experiences of people with disabilities. Ultimately, these ideologies can act to cover up discriminatory discourse from being addressed and corrected.

### **Considering the Individual**



The habit of lumping disabilities together under one label undermines the identity of the individual. An identity can be understood to be a linguistically constructed membership within a social group (Kroskrity 2004). Because of this, referencing people with a wide range of disabilities by the same terms like special needs, disabled, or handicapped acts to strip them from any group they may personally identify with and lump them with a group of people that are quite different from them. As a result of these generalizing terms going unchallenged, individuals with disabilities are often treated inappropriately due to an erroneous assumption about their disability. People with a visible physical disability are commonly assumed also to have a mental disability (Anner 2016). The treatment they receive makes this assumption clear, for example, a waiter might direct questions about a person's menu choice towards their companion rather than addressing the person in a wheelchair (Anner 2016). While ignoring people due to a real or assumed disability is inappropriate in any instance, it represents an example where lack of linguistic specificity resulted in subsequent exclusion from social settings.

Understanding what is at stake within linguistic specificity offers insight for how the SMD can overcome one of its major critiques: the erasure of the individual. Critics of this aspect of the SMD maintain that by taking focus away from the individual people with disabilities they are

left to be recognized as one homologous group (Williams 1999). As discussed previously, people experiencing degenerative illness do not have identical concerns towards their disability as a person with a fixed disability, as discussed previously. Rather than allowing this limitation to justify an abandonment of the SMD, attention should be paid to the importance of using specific language when discussing people with disabilities. Society can have a ranging impact on people with impairments depending on a number of factors including first and foremost the nature of the impairment. Becoming more specific with the language used to describe people with disabilities would make clearer the unique challenges society presents for them. As a result, society could become more inclusive by being informed on how to provide the appropriate adaptations for a specific disability rather than attempting a one size fits all solution.

### **Stigma via Language**

The components of language discussed throughout this paper, such as ideologies, discourse, jokes, slurs, and metaphors about disability aid in the recognition of stigma. Understanding the language surrounding disability as one aspect of the many societal factors contributing to oppression within the SMD allows for an examination of specific ways people experience limitations not based on their impairments, but

because of the way language can work to condone, normalize, and/or perpetuate this type of discrimination. Though language can be used to perpetuate the stigma held within a society, it also has the power to create avenues for inclusion.

### **The Use of Humor**

Keith Basso's "Portraits of 'the Whiteman'" is a linguistic and ethnographic work that details examples of how the Western Apache use humor to make sense of their world and relay serious information (Basso 1979). Through the use of satire and imitations of typical behavior of Anglo-Americans, the Western Apache represent their interactions with 'the Whiteman'.

In a similar way, individuals with disabilities are utilizing humor as a way to approach difficult topics surrounding disability. Zach Anner is an example of one such comedian who through the name of his book alone "If at Birth You Don't Succeed" proves himself to be approachable and willing to talk about things that typically are avoided in social interactions between people with and without disabilities (Anner 2016). Basso describes how the role of the "joker" is allowed certain moral immunity, where behaviors that would typically not be accepted are extended an exception (Basso 1979). In this way, comedians are able to broach topics and make points, such as challenging slurs and labels, that as outlined

are typically met with people angrily defending their right to speech (Hill 2009). People without disabilities often feel unclear about appropriate behavior, and as a result, react by excluding people with disabilities (Hart et al. 1987) By creating a space to discuss difficult topics, people without disabilities gain knowledge about interacting with people with disabilities.

### **Language within Policy**

The Individuals with Disabilities Education Act (IDEA) was established in 1975 to ensure the presence of services to children with disabilities and helps control how states provide early intervention and special education (Individuals with Disabilities Education Act 2004). Yet still, the justification for the social exclusion of people with disabilities within school systems utilizes the same discourse used to rationalize racial segregation and exclusion (Ferri and Conner 2005). Ferri and Conner offer an assessment of school policy during racial segregation and discuss how the language is similar to the current justifications provided for the separate classrooms for children with and without disabilities. They compared how disability is conceptualized as an innate biological difference rather than a social issue to justify the need for different classrooms to accommodate these unavoidable differences, which is how race was explained before *Brown versus the Board of Education*. Attempts toward integration have been urged and

compromises are made that lead to integration for parts of the school day, to then remove the individuals with disabilities before certain subjects.

Often these “exceptional classrooms” will have children with both physical and mental disabilities, with a wide range of needs and abilities, being taught the same lesson due to failure to adapt learning material in an individualized manner. As a result of this segregation, people without disabilities are not given the opportunity to learn how to interact with people with disabilities. It is not surprising then that children who are taught that there is something about children with disabilities so fundamentally different that it justifies exclusion often become adults who assume the same.

This shallow level of integration into school brings to mind the study presented earlier where people's behavior towards a person who was visibly physically impaired was observed and found their behavior and speech to be extremely controlled and inauthentic (Kleck et al. 1999). Within this example, it is clear how people's impairments are resulting in oppression and exclusion, creating disability, as the SMD outlines.

However, this has happened even with attempts by policies like the IDEA and Americans with Disabilities Act (ADA) to correct the burden society places on people with impairment. An approach incorporating the advantages of both a social and medical model of disability, as outlined in this thesis, would lead to more meaningful inclusion.

## **Stephan Hawking**

Stephan Hawking represents someone who has been able to bridge a gap between physical ability and environmental demand within a medicalized state while others have not. A further discussion of his specific case will be used to show not what is currently possible for everyone with a disability, but rather, what could be possible if societal values adapted to cooperate within the medicalization of disability because of the different adaptive equipment poses to the voice and pace of language.

Hawking developed amyotrophic lateral sclerosis at the age of twenty-one in 1963, which progressed to the point where he is now paralyzed and uses a wheelchair (Mialet 2012). In addition to this, complications with pneumonia led to the loss of his voice in 1985. Already a “genius-physicist” at Cambridge University, Hawking utilized adaptive technology to complete his education and continued to become one of the world’s most famous scientists (Mialet 2012: 11).

He uses a speech device technology called the Equalizer, where text is selected to either be spoken immediately or saved for later. While text to speech technologies are hardly limited to world famous scientists, the acceptance he receives using it is rarer. People speak on average 150-200 words per minute, compared to around twenty words a minute using the Equalizer – which is considered rapid for this technology (Mialet

2012). This is an example of new demands adaptive technology makes of society, the commitment to not interrupt or lose focus with someone who is communicating around nine times slower shows why it is important to include a social approach to disability alongside a medical one.

In addition to the patience people extend Hawking's reduced pace, he also has access to engineers that will tailor technology to fit his preferences. Hawking's has continued to use the Equalizer, even though it has become outdated and inferior to other adaptive technologies, such as EZ Keys, which utilizes word predictive technology and integrated systems that operate quicker and more efficiently (Mialet 2012). Expert engineers are available to Hawking and have helped modify the Equalizer so that he has been able to stay with the technology he is most comfortable with rather than switch over to a system he feels less secure with (Mialet 2012). This behavior is described as if it is peculiar. However, people without disabilities are given a wide range of options when it comes to communication devices (e.g. Apple versus Android) and have been seen to display loyalty towards ones they are familiar with despite shifting trends, without garnering the same reaction. Thus, it is not Hawking's preference for what he is familiar with that is unusual; it is the fact that he can maintain an outdated system in ways not available to most people with disabilities that make his case stand out.

In addition to the dramatically reduced pace that adaptive speech devices offer there is also the matter of voice to consider. Some devices allow for certain gender or age categories to be selected, but the voice is still recognizably computer generated. This presents a number of challenges for the people using these devices.

One such hurdle is that of identity, which can be explained by citing a conversation that took place between the Queen of England and Stephen Hawking. At a charity event in 2014, Queen Elizabeth II asked Hawking, “have you still got that American voice (Edgar 2014)?” Accents can act as subtle way to transfer significant aspects of a person’s identity. While this ability to hide this aspect of their identity can certainly be seen as a positive as well as a negative, it ultimately represents a difference between people with and without speech devices that at the moment, technology is not bridging. This situation again requires the social response of acceptance and patience. It might not seem like a pressing limiting factor relative to other challenges faced by people with disabilities. However, while their status as someone with a disability removes them from the shaky category of people “without” disabilities; their lack of ability to speak with their regional accent removes them geographically in a way as well.

I argue that a main limitation speech devices have is the lack of an ability to provide the potential for spontaneity to the user. The user has



set parameters for how they can vocally engage with their world, and it is preprogrammed for them. People without speech devices are capable of changing their intonation and cadence at any time within a sentence to convey meaning. This is a limitation that could be taken on by both technological and social means. Speech devices could be further programmed to vocalize the message in specific accordance with the meaning of the user. However, on the social side, people could also agree on certain queues to signify meaning; similar to the way people have agreed that certain emoji's after text signify emotions in a more specific way than text alone can accomplish.

The support system surrounding Hawking's is what enables his ideas to be distributed worldwide. The acceptance of his difference is what allows the world to benefit from what he has to offer, and it is a better world for it. If that level of support and acceptance could be translated to every child in classrooms across the United States, rather than simply being supplied with a medical diagnosis and adaptive equipment that might or might not work well for the individual in question, it is difficult not to wonder how many other visionaries and geniuses we might realize live among us.

## **Conclusion**

The consideration of how the language surrounding disability contributes to the oppression of people with disabilities is one-way anthropology is able to engage with the SMD to consider society's role in disability.

Changing names for disabilities is a continuous task because the concept behind the word has not been addressed. Additionally, while using person first language is significant and works to protect individual identity, it is only important because of the negativity disability faces. Not many people would object to being called a homeowner and request "person who owns a home" instead (Estroff 1993) Understanding this, any attempt to resolve the damaging effects of slurs, labels, or terms for the lives of people with disabilities need to be made at the conceptual level of disability (Galvin 2003). In the meantime, people with disabilities should be sought out for all conversations relating to disability to avoid adding to the silencing experienced.

## CHAPTER 4: TECHNOLOGIES

Technology represents a field that has the potential to bridge the gap between personal ability and environmental demand. Even though there is a widespread use of adaptive technology used to bridge different gaps for people, society does not react similarly to the range of technologies utilized. Incorporating technology within classroom settings can increase the learning potential for children with disabilities while creating a more even playing field for them to interact with their peers in an inclusive environment (Pearson and Bailey 2007). However, as discussed previously, adaptive technology is not a stand-alone fix and there are policies in place that stand in the way of allowing this technology to operate as both a medical and social solution.

The use of corrective lenses acts to equalize a broad spectrum of ability when it comes to eye sight. People who previously would not be able to operate a vehicle are able to with the use of these lenses. Though this type of adaptive technology has high visibility, it does not have as much of a stigmatizing result as other technologies discussed later. I argue that this is due two important factors. The first is the seamless nature in which it bridges the gap between the individual's ability and environmental demand. That gap is filled completely by the adaptive technology and does not require additional time or patience on the part of

peers. In fact, technology has gone so far to even make this technology invisible to society via the use of contact lenses, so even the aspect of society aesthetic acceptance can be subverted. The second main factor in the cultural acceptance of corrective lenses is the widespread nature of this technology. 61% of people within the United States use some sort of corrective lenses (Bruggink 2012). The widespread nature of this impairment goes a long way toward garnering cultural acceptance.

I argue that these factors influence poor eyesight to not be considered a disability, but rather an impairment that can be overcome with the use of adaptive technology. The seamless nature corrective lenses bridge the gap for people is not a reality for all forms of adaptive technologies. Nevertheless, they should represent a goal to work towards. It is not enough to provide a piece of equipment that provides a person with an ability they previously did not have, but rather the goal should be to provide that ability in as similar a manner as their peers. As discussed in the previous chapter, if this had been the goal for adaptive speech devices, the option to utilize accents would have been present. Similarly, many other impairments will never afflict 61% of the population, however, that is not the takeaway. Rather, that should be used as an example of what cultural acceptance can accomplish. That level of acceptance does not necessarily require the majority of a population to have a vested interest, rather, it could be gained through programs and

policies informed on the importance of the SMD. The SMD is positioned to help explain why medical answers (ie. adaptive technology created by people within a medical profession) do not work to completely bridge the gap between personal ability and environmental demand.

One of the requirements for something to be "durable medical equipment" as defined by United States Medicare is for it to not be generally "useful to an individual in the absence of an illness or injury" (42 CFR 414.202). As a result of this condition, technology used for medical purposes cannot be streamlined or integrated with popular technology, even if it would be more cost effective (Litvak and Enders 2001). This is a loss of a massive opportunity to reduce the gap of difference between people disabilities and without. Instead, devices continue to carry the stigma of "handicapped devices" that represent another aspect of life that is difficult to relate to for people without disabilities (Litvak and Enders 2001).

My brother's Dynavox is a touch screen device that displays preprogrammed boxes of words that when pressed speak out loud. The screen is the exact size of an iPad except the Dynavox is about five times as thick and heavy. As mentioned before, it takes a few minutes to start up and a long time to charge. When the charger breaks, a new one has to be ordered online because it does not use a popular connection, though my father usually keeps two on hand to avoid leaving my brother without

a form of communication. All of these challenges would be significantly mitigated if not erased if medical equipment was allowed to benefit from the improvements made to devices that are marketed to the masses. This solution would not even require the mainstream device companies cooperation, as independent software companies could be contracted to make applications for the already existing technologies ubiquitous within today's society.

### **Recreational Technology**

Video games require considerably less physical ability than their real life representations, however, they have not been the inclusive haven that they have the potential to be. Popular gaming systems such as Microsoft's XBOX and Sony's PlayStation have not developed options for adaptive controllers that could accommodate a wider range of abilities. Games via a computer have the option to be played with a joystick, which is more user-friendly for people with reduced fine motor control, but even this is not without its limitations. Many games played on the computer would be playable by people with reduced motor control if it were not for the timer component present on many games. The ability to deactivate the timer function and simply complete the game at an individual's own pace would open up the world of gaming to a wide range of abilities; however, that option is not mainstream.

More inclusive controller options and the ability to deactivate a timer represent two relatively simple technological modifications. I argue that it is not the complexity of the adaptation that is holding these improvements back but rather the lack of outreach and understanding of disability. Occupying the liminal state described in the previous chapters, people with disabilities do not gain the same market research attention as fully included members of society do which would open up this type of dialog and lead to inclusion. It even has the potential to work in a type of feedback loop by leading to adaptive technology that could be utilized in more formalized settings such as education or rehabilitation, as has been attempted with the Nintendo Wii (Holzinger et al. 2012).

## **Conclusion**

Conceptualizing disability as a problem with society rather than the individual with an impairment allows for a broader approach for solutions (Oliver 1990). Incorporating people with disabilities into classroom settings, using humor to approach disability, understanding the broad range of reactions to disability via cross cultural examples all represent social treatments for disability. Social treatments need to be implemented along side medical ones to ensure people's needs are not being reduced to one aspect of their lives. Anthropological perspectives reveal the importance of a multifaceted approach and demonstrates how to merge the valuable aspects of both the medical and SMD.

## CHAPTER 5: CONCLUSION

John McKinlay uses the analogy of a river to illustrate issues surrounding allocation of attention and funding of certain medical issues (McKinlay 1979). A distinction is made between upstream and downstream factors contributing to health. An upstream approach would include considering the political and economic forces that create risk for certain people within a society. A downstream approach, however, focuses on the individual level and the specific health and behavior that led to the illness at hand. As the name implies, the downstream approach ignores the larger aspects influencing health and if mitigated stand to translate into the reduction of risk for an entire group of people.

In the case of disability, neither the upstream nor downstream factors can be ignored. This analogy illustrates what is at stake in the integration of the medical and social model of disability. Neither the view of disability via purely medicalized terms or social ones seem to capture the complex dynamics at play accurately. The medicalization of disability has provided insurance that covers adaptive technology, however, if it does not fulfill what is valued within a given society it will not translate into the reduction of stigma or social exclusion. On the other hand, sole focus on the social aspects of disability ignores the critical medical assistance some people with disabilities rely on to survive.



I argue that if these complexities can be anticipated rather than reacted to, there would be a more seamless transition between medical assistance and social acceptance. Using the example previously outlined about the speech devices, while they do provide the main service of acting as a voice if the social factors involved in using this technology were considered during production they might come with a range of accent options. The goal is to bridge the gap between people's physical limitations and environmental demands. While some solutions tackle one side of this gap more directly than the other, there should be a constant anticipation of how a proposed solution will interact with the range of realities facing disability. If this attention was given to both sides of the gap, the requirement for medical devices to be minimally useful for people without a disability, which holds merit within the medical model, would have been troubleshoot by consideration of the social implications (Litvak and Enders 2001).

### **Disability within Childhood**

The Individuals with Disabilities Education Act (IDEA) was established in 1975 to ensure the presence of services to children with disabilities and helps control how states provide early intervention and special education (Individuals with Disabilities Education Act 2004). Yet still, the justification for the social exclusion of people with disabilities within school systems utilizes the same discourse used to rationalize

racial segregation and exclusion (Ferri and Conner 2005). Ferri and Conner offer an assessment of school policy during racial segregation and discuss how the language is similar to the current justifications provided for the separate classrooms for children with and without disabilities. They compared how disability is conceptualized as an innate biological difference rather than a social issue to justify the need for different classrooms to accommodate these unavoidable differences, which is how race was explained before *Brown versus the Board of Education*. Attempts toward integration have been urged and compromises are made that lead to integration for parts of the school day, to then remove the individuals with disabilities before certain subjects.

Often these “exceptional classrooms” will have children with both physical and mental disabilities, with a wide range of needs and abilities, being taught the same lesson due to failure to adapt learning material in an individualized manner. As a result of this segregation, people without disabilities are not given the opportunity to learn how to interact with people with disabilities. It is not surprising then that children who are taught that there is something about children with disabilities so fundamentally different that it justifies exclusion often become adults who assume the same.

This shallow level of integration into school brings to mind the study presented earlier where people’s behavior towards a person who

was visibly physically impaired was observed and found their behavior and speech to be extremely controlled and inauthentic (Kleck et al. 1999). Within this example, it is clear how people's impairments are resulting in oppression and exclusion, creating disability, as the SMD outlines. However, this has happened even with attempts by policies like the IDEA and Americans with Disabilities Act (ADA) to correct the burden society places on people with impairment. An approach incorporating the advantages of both a social and medical model of disability, as outlined in this thesis, would lead to more meaningful inclusion.

As history has already made clear, there is no such thing as separate but equal. The lack of integration of people with disabilities within our school systems leads to an inferior educational experience. Free and public education is the cornerstone of democracy, and as such, any level of denial to it represents a form of oppression, as identified within the SMD. Strengthening the IDEA to require a truly inclusive learning environment and challenging policies that limit adaptive technology would go a long way to ensure that both medical and social needs are met.

### **Adults with Disabilities**

Graduation from high school represents a time of transition for everyone. For people with disabilities, however, it represents not only transition but also potentially a considerable loss of resources. At a time that parents' responsibility and involvement typically decreases for their

children, parents of people with disabilities face an increase of responsibility (Thorin et al. 1996). This demand is exacerbated by the lack of clarity individuals with disabilities and their parents receive about the services available to them (Stewart 2009). Also, for the individual with a disability, graduation from high school can also represent a shift towards increasing social isolation (Stevenson 1997). These factors can disrupt the way of life for a family and leave them feeling helpless.

The struggle faced due to this transition illustrates the profound impact social factors of disability can have. Even though nothing may have changed biologically, this still represents an incredibly stressful event in the lives of people with disabilities and their families (Trainor 2010). An interdisciplinary approach to resource management is a common suggestion for improving this transition (Stevenson 1997 and Stewart 1997). Guidance counselors should be working with local resource groups to be able to provide a plan for individuals with disabilities and their parents months before graduation (Steward 1997). Depending on what the nature of their impairment, these plans might include potential employment, secondary education, or activity centers geared towards people with disabilities.

There are non-profit organizations focused on providing opportunities for socialization to people with disabilities. Among Friends has been in operating in Norman, Oklahoma since 2003 ("Among Friends

Norman” 2017). It is open Monday through Friday from 9:30 AM - 4:00 PM and costs \$100 a month. It offers to “help break the cycle of isolation, loneliness, and depression” (“Among Friends Norman” 2017). These type programs are important and beneficial due to the current social exclusion people with disabilities experience, especially as they reach adulthood. However, there still remains an element of exclusion within these programs as they are often exclusively for people with disabilities.

Through researching the extent to which the medical a social models of disability are capable of providing a meaningful understanding of what type of care is needed by people with physical disabilities within the United States today, it has become clear that it is an integrated medical and social model. This is a compromise that will find increasing support as the ethnographic research extends beyond the scope of medical and applied anthropology. In addition, it became apparent while considering the number of complexities within these issues that it is important to consult people with disabilities about both social movements and proposed policy changes. In order to achieve the level of interdisciplinary approaches suggested throughout this thesis, it is critical insurance companies, educational systems, technological companies, and medical teams cooperate with each other. If these goals could be implemented, the United States could offer a more inclusive as well as healthy environment for people with physical disabilities.

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