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Complexity and Conflict: The Interplay of Policy, Perception and Language in Post ADA America

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Complexity and conflict: The interplay of policy, perception and language in post ADA
America

by

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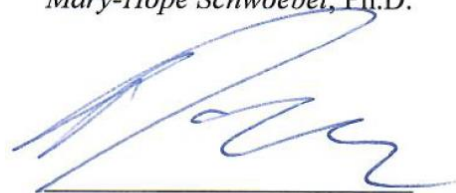
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Abstract

The purpose of the dissertation is to examine the language used to discuss disability and the attitudes and perceptions that the general American public has about people living with disabilities. Using the transformative research and evaluation method, the content analysis study examines the use of "deficit perspective language" versus "non-deficit perspective language" as defined by Mertens in materials available to the general American public that address the five areas described in the World Health Organization matrix on community rehabilitation for people with disabilities. The mixed methods study explores both the frequency of deficit perspective language and the frequency non-deficit perspective language as well as the themes such language conveys to the general public. The research provides person centered perspectives addressing academic literature gaps relating to the topic of disability from a non-clinical perspective, using muted group theory, complexity theory, social justice theory and critical disability theory. From a conflict resolution perspective, the study aims to provide insight and ideas based on Mayer's paradoxes as related to practitioners' abilities to help fully integrate people with disabilities into their local communities. Using triangulation protocol designed for content analysis the study indicates the potential reasons for continued marginalization of disabled Americans.

Chapter 1: Introduction to the Study

The History of Disability Perception and Policy

Like many minorities in the United States the history of people with disabilities is one of disfranchisement. That disenfranchisement is systematic and stems from all corners of society including, but not limited to the areas of sciences (sometimes pseudo-sciences) religious beliefs, public policies and social and cultural mores with regard to disability (Nielsen, 2012); it is tied to our history and changing beliefs and values as a nation, and while many of the beliefs and values have changed, little has changed the disenfranchised nature of living with a disability in the United States.

Prior to the arrival of the colonists in America, ideas about disability varied with the different tribes. Some Native Americans believed that the spirit picked the body and that as long as the individual contributed to the good of the community in whatever way he or she was capable then there was nothing amiss with the person or the community, other indigenous communities felt that disability was punishment for the actions of other family members (Nielsen, 2012). Nielsen continues by explaining colonialists' beliefs that disability was caused by sin or spiritual uncleanliness guided their treatment of people; often bleeding and other medical remedies at the time were considered a cure but only made situations worse. As America was developing its identity as a nation, disability was an identifying factor like race and gender that precluded people from being full citizens in the new nation.

The time between colonization and the United States coming to its identity as a power unto itself separate from England was for people with disabilities still heavily influenced by Elizabethan era politics in London. In the 1600's the rise of alms houses

or poor houses became a band-aid type of fix for the poverty and disability being displayed on the streets of London. If people were unable to pay off debts due to disability, they were sent to alms houses that were supported by tax dollars called a "poor rate" that was charged to property owners and charitable donations. The same trend began to take place in the United States. New York became the first state to institute a tax on estate owners that would support the "needy" and "dependent" poor. People with disabilities were considered both "needy" and "dependent" and were sent to alms houses to live.

1800-1900's Ugly Laws and Industrialization

During the next hundred years there was significant change for people with disabilities, little of which would be considered actual progress. The rise of circus freak shows as a form of public entertainment often displayed disabled people as main attractions in "freakshow" tents and was often the only way for a runaway disabled slave to make a living in the north (Brune & Wilson, 2013).   After the end of World War I, such displays grew out of favor as they were seen disrespectful to wounded war heroes. One of major complaints from disability rights advocates about the modern movie *The Greatest Showman* was that the movie glossed over the fact that P.T. Barnum made much of his money and fame off of disabled people in his freak shows (Lopez, 2017).

Between the end of the civil war and the full rise of the industrial revolution the medical model of disability began to spread, and the categorization of disability came to be. At the same time people with disabilities were beginning to shun poor houses because they were left to die there instead receive the care they were promised. Out of the medical model perspective came several significant changes simultaneously in regard to

disability. Around this time in the mid 1800's was the pervasive influence of charitable organizations on the enactment of city and sometimes state policy with regard to unsightly activity on city streets. This was any form of begging or performing for money, which was often done by those who had some form disability. The creation of "ugly laws" spread across the major cities in the U.S. Ugly laws held that:

> Any person who is diseased, maimed, mutilated, or in anyway deformed, so as to be an unsightly or disgusting object or an improper person to be allowed in or on the streets, highways, thoroughfares, or public places in the city, shall not therein expose himself to public view under penalty of fine (Schweik, 2009, p. 2).

In denying the rights of full citizenship to people with disabilities, policies were then set in place to virtually guarantee marginalization for centuries to come (Auterman, 2011). By the 1800's there were laws in place to ensure that people with disabilities would be hidden from view and less burdensome to the public.

At the same time ugly laws were being enacted the industrial revolution was in full swing. According to Rose (2017) work-acquired disabilities were seen as badges of honor among men working in factories.   Being disabled on the job and still working meant a man was good at his job and was valuable enough as an employee for the factory to keep employed. If a person was born of "feeble-mind" or an "imbecile" at the early part of the industrial age they were usually given a job in the community or within their family homes that was considered within their capacity.   As industrial capitalism began to take hold physicals were required before hiring that impacted the ability for people with disabilities to get and maintain employment. Rose said:

[T]he "problem" of disability lay not in their actual impairments or the work they did but rather in the meanings attributed to those impairments by policy makers and employers, as well as in how those meanings intersected with a rapidly shifting workplace, changing family capacities, policies aimed at preventing dependency, and the complexity of disability itself (Rose, 2017, p. 3).

Due to the changes in family roles in caring for disabled relatives, they could no longer do so because they now needed to travel to urban areas for work, institutions for people with disabilities began to appear (Rose, 2017). The first institution for the "mentally feeble" was established through the work of Dorthea Dix in New Jersey in 1845. Often people were put in asylums and taught skills that made them useful laborers, some people were returned into society to simple jobs, others were so good at what they did that institutions said they were beyond rehabilitation and needed permanent institutionalization. In reality they became unpaid labor for the institution (Rose, 2017). It was during the time of early institutionalization that terms like "idiot" and "moron" were according to Rose used as diagnosis by psychiatrists. In 1909 postcards with the term "idiot's club" were making the round as common gags of the time. The jokification of disability still happens today.

As employment landscapes continued to shift so did policies regarding the financial help available to people with disabilities. Legislators and policy makers for charities that had long given money to the poor began to feel like many people who were tired of the grind of the industrial era were faking disability. The powers that be at the time struggled with how to separate what they deemed the truly needed from "malingerers". While Rose (2017) contends the intent was

never to keep disabled people from employment, policy makers did just that and

unintentionally began to create disability policy around employment.

1920-1940's Eugenics and the "Faker-in-Chief"

With societal expectations and beliefs around disability beginning to coalesce so

too did legislation and policy around the treatment of disabled people, especially with the

medical technology being developed at the time. In 1907, Indiana became the first state

to force sterilization on the "feeble-minded" because Dr. Harry Sharpe had been

experimenting with vasectomies on male patients in the Indiana State

Reformatory. These forced sterilizations became the beginning of the eugenics

movement in the United States. The Eugenics Record Office opened in 1910 in New

York. Out of it came recommendations for the treatment of disabled people and people

of color in terms of immigration, marriage, sterilization, procreation and

institutionalization.

States across the country began implementing laws based on the information

coming out of the Eugenics record office. Federal policy was also set by it. In 1924 the

Immigration Restriction Act was bolstered by the eugenics movement with President

Calvin Coolidge saying, "America must be kept American" (Museum of Disability

History, 2018, para. 7). The Immigration Restriction Act was not repealed until 1965. In

1927 the court case Buck v. Bell (Museum of Disability History, 2017) set the stage for

nationwide forced sterilization of those with disabilities. It is important to note here that

while forced sterilization was repealed in Virginia in 1974, it has never been federally

declared unconstitutional.

The Buck v. Bell Supreme Court Case upholds the compulsory sterilization of defectives. "Three generations of imbeciles are enough" stated Justice Oliver Holmes. In an 8 to 1 decision, the court legitimized the Commonwealth of Virginia's law on sterilization that was not repealed until 1974. The case legitimated eugenic sterilization laws throughout the entire United States. (para. 8).

In 1932 Franklin Delano Roosevelt was elected President of the United States. Scholars widely agree that he is the first person with a disability to hold such a high federal office, although Roosevelt, his inner circle, and the press would do everything in their power to keep FDR's post-polio paralysis hidden from the American public and the world (Brune & Wilson, 2013). The only major achievement for disabilities that FDR championed was the creation of the March of Dimes created in 1938, although in 1938 it was called the National Foundation for Infantile Paralysis; its goal was to help eradicate polio.

His election brought a certain amount of hope and pride for people with disabilities, especially those with "post-polio syndrome", that was until they realized that Roosevelt was attempting to pass as fully able-bodied. In hindsight his doing so would bring greater stigma and harm to the disability community. "many sought to follow FDR's example, in spite of considerable physical and psychological pain. Others eventually came to the conclusion that it was futile to emulate the "passer-in-chief" who was a wealthily white man" (Brune & Wilson, 2013, p. 14).

Roosevelt and his handlers went to great lengths to hide his paralysis. He was never lifted out of his wheelchair in public and was often seen on the arm of his son,

whom people were told was a bodyguard, in reality his son was holding him up and helping him move to his position. The press never took pictures of FDR looking "weak" and pictures of him in his wheelchair were rare. He knew exactly what everyone was doing and referred to it as the "splendid deception" (Brune & Wilson, 2013, p. 17).

> An agreement was struck: the existence of FDR's handicap would simply be denied by all. The people would pretend their leader was not crippled, and their leader would do all he could to not let them see that he was (Brune & Wilson, 2013, p. 18).

> Much of what FDR did was and is considered by today's standard as "passing".

Passing is "disguising the visible signing of impairment to...diminish the stigma associated with disability" (p. 19). The example that the general public gleaned from FDR was damning to many post-polio survivors' doctors, therapists, and family members who encouraged them to try harder to restore muscle function and mobility and emulate FDR in becoming a 'cured cripple'.

> As their bodies became more disabled, some polio survivors who had successfully passed realized how disabled they had always been and began to more fully accept a new identity as an individual with a disability. Finally, some who had fought for years to emulate FDR abandoned him as role model. The fiction that you could be anything or do anything you wanted simply could not be sustained (p. 21).

> In writing about him now many disability advocates and historians acknowledge

that the handling of FDR's disability, both in perception and missed legislation

opportunities, was setback for the advancement of people with disabilities (Brune & Wilson; 2013, Gallagher; 1994, Sheed; 1995, Wilson; 1998).

Public law 176 was signed by President Harry Truman in 1945. The law created "National Employ the Handicapped Week" to encourage awareness and create more employment opportunities for people with disabilities. In 1988 Regan changed it from a full week to a full month and now it is called "National Disability Employment Awareness Month". The Department of Labor says it has been "celebrating inclusion for more than 70 years". (DOL, 2018, para. 1). John F. Kennedy became the next president to address disability on a public level after the National Association for Retarded Citizens was established in 1950.

1950's - 1990's National Association for Retarded Citizens to ADA

Until the 1950's children with intellectual (and often physical disabilities) were institutionalized. These children, many who died as adults in institutions, were often hidden and families did not acknowledge them. In 1952 following the establishment of the National Association for Retarded Citizens a memoir published by Dale Evans Rogers called *Angel Unaware* pushed for the de-stigmatization of families and children with intellectual disabilities. In 1963 Kennedy requested congress find a way to reintegrate institutionalized people into society. Thus "sheltered workshops" began replacing asylums and institutions. Kennedy's family established the "Special Olympics" in 1968.

The 1970's brought legislative and policy changes for developmental disability issues.

Developmental Disabilities Services and Facilities Construction Amendments were passed in 1970. The amendments gave states extensive responsibilities to establish comprehensive programs to provide services for people with developmental disabilities. It also offered the first legal definitions of developmental disabilities. Grants for interdisciplinary training in higher education were also included for those who provided services to developmentally disabled individuals (Museum of Disability History, 2014, para. 11).

1973's Rehabilitation Act created Section 504 which made discrimination "against the handicapped" the first time that disability was addressed in federal legislation. Additional legislation in 1973, the Federal-Aid Highway Act, demanded that curbs be constructed with entry and exit points for wheelchair users. In 1976 the Higher Education Act enabled students with physical disabilities to seek services that allowed them to attend college. The United Nations General Assembly declared 1981 the "Year of Disabled Persons" asking governments worldwide to include individuals with disabilities in mainstream society. President Regan would then declare the years 1983-1992 the "Decade of Disabled Persons".

Improvements for people with disabilities, both in and out of the public sphere moved slowly; long gone were institutionalization and sterilization, medical treatment continued to improve but access, both physical and social, to the public world lagged until The Americans with Disability Act was passed in 1990.

For the first time accommodations for physical access, educational needs and employment adjustments were required by law; there was even an amendment added to the law in 2008; enforcement of those laws still lapses. People with disabilities often bear

the burden of having to pursue legal action so that the laws be enforced (Johnson, 2003). What is more, it is still legal to pay individuals with disabilities below minimum wage and if individuals with disabilities make more than the federal poverty level as individuals or as married couples they risk losing SSD benefits that often pick up the cost of their medical care (Evans, 2015). It is for that reason that many individuals with disabilities are not employed or married and often perceived as a burden on society (Stasio, 2010).

July 2015 marked twenty-five years that ADA has been law in the United States. Some see this as a cause for celebration. New York held the first ever Disability Pride Parade (Dobnik, 2015), for others slow change over twenty-five years is still a reminder of how far disability rights and full inclusion as yet to go. Jeffery Pfeffer (2015) believes that American society has a long way to progress. An employee of Stanford Business School, Pfeffer travels for his job, he uses a wheelchair as his main source of mobility. More than once Pfeffer has been denied access to flights because he did not pre-notify the airline that he would need assistance to the jet way. He points out that during the original construction of the ADA airlines and airports received exemptions from ADA compatibility unless they were pre-notified by disabled passengers. After twenty-five years that has yet to change. He maintains that such policy is along the lines of colored and whites only entrances – it is not equal treatment as most people codify that concept. Pfeffer also wants the public to be aware that the inequity in disability rights affects everyone because while only five and a half percent of Americans ages sixteen to twenty report a disability, the numbers of reported disability rise with the increase in age "Aging makes disability concerns almost universal" (Pfeffer, 2015, para.

5). The World Health Organization [WHO] (2011) backs Pfeffer's claims and calls for

not only greater access but also greater inclusion across society in general.

The policy and politics of disability in the twenty-first century

Since disability can be a complicated issue, it is important to recognize its

complexity and the impact that complexity has on the perceptions of disability.

Health	Education	Livelihood	Social	Empowerment
Promotion	Early Childhood	Skills Development	Personal Assistance	Advocacy and Communication
Prevention	Primary	Self-Employment	Marriage and Family Relationships	Community Mobilization
Medical Care	Secondary & Higher	Wage Employment	Culture and Arts	Political Participation
Rehabilitation	Non-Formal	Financial Services	Recreational Leisure and Sports	Self-Help Groups
Assistive Devices	Lifelong Learning	Social Protection	Justice	Disabled People's Organizations

Figure 1. WHO CBR Matrix

In 2010 the World Health Organization (WHO, 2010) started a global initiative

called "Community Based Rehabilitation" (CBR). The purpose of the initiative is to

provide people with disabilities the opportunity to be fully active in their

communities. There are five areas the initiative covers: health, education, livelihood,

social, and empowerment. Each area is then broken down into further areas.

Information in the CBR Matrix is important because it provides a pre-determined

set of criteria to examine with regards to perceptions on disability. Using these concepts

as a guide in seeking out insight on the disability experience or public's perception of it

saves time as allows for the CBR Matrix to serve as both a building block for this study and a bridge to what is trying to be achieved on a global level in terms of living with a disability. The WHO (2010) CBR Matrix and its global initiative sprang from the United Nations' Convention on Rights for Persons' with Disabilities, which in turn borrowed much of its structure and conceptualizations from the Americans with Disabilities Act. Familiarization with the ADA provides a basis for helping to understand the perceptions of disabilities from the policy end as well as public perspective and the lived experiences of those with disabilities.

The Policy

The Americans with Disabilities Act of 1990 was the latest incarnation of policy revisions and changes that dated back as far as the founding of the nation (Nielsen, 2012), with the earliest 'modern revision' taking place in 1965's Rehabilitation Act Amendment also known as Title V (Vaughn Switzer, 2003). ADA is broken down into five titles. Each dealing with various aspects of public life that people living with a disability might need adjustments.

Title 1. Employment Discrimination: In an effort to make employment more accessible to people with disabilities Title I deals with employment discrimination. The Equal Employment Opportunity Commission is responsible for enforcement of Title I. Under this title employers are required to provide employees with disabilities who are otherwise fully qualified with a full range of employment and advancement opportunities. Title I also prevents potential employers from asking specific disability related questions to potential employees. It is Title I of the ADA that requires employers

to provide employees with disabilities reasonable accommodation that does not put undue hardship on the employer.

Title 2. Responsibilities of Local and State Governments: Title II regulates the activities of states and local governments with regard to the ADA, specifically subtitle B references that all public transportation is accessible to people with disabilities. All areas of public life must be accessible to people with disabilities in regard to architecture or the use of assistive devices, people or animals. Like Title I governments are exempt if the accommodations put financial or otherwise unreasonable strain on the public entity. Implementation of Title II fails under the enforcement of the Department of Justice (DOJ). Any person wishing to have reasonable accommodation made must notify the public entity in advance and any complaints must be filed with the DOJ must be also given to the offending entity ninety-days in advance of the lawsuit filing (currently the only avenue available for any ADA title enforcement) so that said entity public or private can prepare for litigation (Johnson, 2003).

Title 3. Public Accommodations, Services and Transportation provided by Private Entities: Title three regulations for private entities are identical to the requirements for state and local entities that serve the public. Enforcement is done by the DOJ via lawsuit that must be submitted to the private company first before it is filed so that said company has time to prepare for the impending lawsuit. Accommodation that causes undue hardship on the business does not have to be provided.

Title 4. Telecommunications and Closed Captions: Title IV regulations cover phone relay systems (TTY systems) and closed captioning for all major phone and cable systems and public announcements. The Federal Communications Commission is

responsible for ensuring compliance and dealing with complaints that come as a result of Title IV violations. Any entity that receives federal funding is required to comply with Title IV.

Title 5. Miscellaneous Provisions: Title V ties ADA to previous legislation and other government entities that may play a role in the implementation of Titles I-IV, such as the Architectural and Transportation Compliance Board. One example would be the ADA tie into Section 504 of the 1973 Rehabilitation; often accommodations for physical changes made to accommodate physical settings in schools for students with disabilities fall under the 1973 Rehabilitation Act but can be pursued through Titles II and III of the ADA.

The politics of the ADA. ADA has been law for over twenty-five years, it is law that faced harsh criticism during its construction and passing and still today it faces continued criticism, not for the same reasons as twenty-five years ago, but for being more of a platitude for people living with a disabilities than the actual promise of inclusion it was intended to be (Johnson, 2003; Vaughn Switzer, 2003). Criticism of the ADA falls under three main areas: definitions, loopholes, and enforcement.

Defining ADA. The definitions or lack thereof built into ADA are arguably the basis for the dissatisfaction with the law. When it was originally written in 1998 there were no solid definitions about who was and was not eligible for protection under ADA. Phrases like "reasonable accommodation" and "undue hardship" were also left undefined. In a 2002 speech to Georgetown Law School Justice Sandra Day O'Connor "called ADA an example of what happens when ... the sponsors are so eager to get something passed that what passes hasn't been as carefully written as a group of

law professors might put together, It leaves lots of ambiguities and gaps and things for courts to figure out" (Johnson, 2005, para. 5-6). According to Vaughn Switzer (2003) and Johnson (2005) O'Connor and the federal court systems dismantled the functionality of the ADA by creating so many contradictory rulings with regard to its application that it rendered the law moot. Not only did the vague language hamper the ADA before it could really be useful, the same language opened the door to legislative loopholes and enforcement enigma.

  Legal loopholes. Tom Harkin (D-IA) was one of the bills co-sponsors in the Senate. Harkin and several of the bills co-sponsors and supporters including President George H.W. Bush and Bob Dole (R-KS) all knew someone affected by a disability and saw the ADA as a long time in coming, but the vagueness of the purposes, and writing of the ADA proved difficult to garner support for according to Johnson (2005); Nielsen (2012) and Vaughn Switzer (2003); many support and advocacy groups for people with disabilities supported it, others did not. Business groups decried the cost of accommodations despite no one having a real idea of what accommodations might cost, especially as "reasonable accommodation" and "undue burden" remain undefined in the legislation. Gay rights advocacy groups wanted HIV/AIDs patients included, but religious groups threatened to withdraw support if ADA coverage included the HIV/AIDs patients.

  In an effort to get the bill passed the deals were made that further weakened the bill. Vaughn-Switzer (2003) chronicles the exchange between Senators Harkin (D-IA) and Hatch (R-UT) over the cost of implementation. According to Vaughn-Switzer, Hatch suggested tax subsidies for small business that would be financially impacted by trying to

comply with the ADA. Harkin accused Hatch of trying to kill the bill because any law that was attached to the tax code had to originate in the house, which Harkin claimed would never happen. As a result, the senate decided that if an accommodation was found to be too costly under Titles I-III, then the employer/business/entity was not required to make said accommodation. It was this legal wrangling and later court decisions that prevented plaintiffs from garnering financial damages from an ADA complaint – they could only sue to request accommodations be made and the enforcing entity was responsible to ensure the accommodations occurred.   This is the only civil rights legislation where plaintiffs cannot garner monetary compensation for physical or emotional impact of non-compliance (Johnson, 2003). At present there is no other way beyond a lawsuit for people living with a disability to request accommodations be made under ADA Titles II and III.

       Enforcement. Enforcing ADA compliance depends under which title the complaint falls. The EEOC is in charge of all Title I complaints as related to employment. Titles II and III are enforced by various departments in the DOJ depending on the complaint and the FCC is in charge of dealing with complaints coming from Title IV. The problem of enforcement is two-fold. According to Vaughn Switzer (2003) and Johnson (2005) the various entities in charge of enforcement have changed depending on administration. That is to say that the enforcing entity under George Herbert Walker Bush was different than the enforcing entity under Bill Clinton and yet again different under George W. Bush. As administrations rearrange and reassign and as court cases change interpretation of the ADA it becomes more and more difficult for those seeking compliance to know where to turn, especially if the complaint might fall under multiple

titles. What adds to complication according to Vaughn Switzer and Johnson is that there is no vehicle to ensure that once a court finds in favor of the plaintiff, who bear the burden of proving a situation non-ADA compliant, there is no way to guarantee accommodations are made, especially where private businesses are involved.

Attempts to better define ADA

In 2008 Congress attempted to eliminate the vagueness and better define elements included in the ADA. According Falstad (2015) Congress endeavored to further define several basic concepts of the original 1990 ADA. Those concepts included disability and discrimination. The 2008 definition of disability according to the ADA Amendment states that a person must have a physical or mental impairment that is long term, ongoing or permanent in nature that affect the major activities of daily life; such an impairment must be recorded by proper authorities and the individual must be considered to be impaired.   Daily life "activities include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working" (Falstad, 2015, para. 5) The impairments definition also includes major bodily functions covering everything from neurological impairments to reproductive functions.

Defining discrimination. Falstad says (2015) discrimination is now defined as: Subject to the provisions of this subchapter, no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of services, programs, or activities of a public entity, or be subjected to discrimination by any such entity (para. 3).

The potential fallout from this definition is one that Vaughn Switzer (2003) pointed out with several court cases and that is that a judge's definition of what is discriminatory maybe different than what congress views as discriminatory and therefore the effectiveness of the law depends on its interpretation.

The newest amendment in 2016 to the ADA that is up before both the house and the senate would require persons needing access to an inaccessible venue to give the business thirty days written notice of the violation, then the business has sixty days to respond to the grievance and one hundred and twenty days to fix the accessibility. According to an email exchanged with Washington state senator Derek Kilmer the goal of the amendment is to cut down of fraud, but there are concerns that the wording of the bill will already increase the burden of public access of people living with disabilities.

The Affordable Care Act and The Trump Administration

A pivotal piece of legislation for people with disabilities was signed into law by President Obama in March of 2010. The legislation required for the first time that all Americans be covered by health insurance. What was particularly important for the disability community was that they would no longer be denied insurance or forced to pay higher premiums because of pre-existing health conditions. The Affordable Care Act (ACA) commonly known as Obamacare has been hotly debated and legally contested since it was signed into law. In January of 2011 a judge ruled parts of the ACA unconstitutional. The decision sparked a legal fight that took the ACA all the way to the Supreme Court who ruled in June 2012 that all major provisions of the ACA were constitutional. However, the election of Donald Trump has seen the ACA come under

threat again with Trump vowing to repeal and replace the legislation. As of 2019 there are new political and judicial decisions that are once again calling the standing of ACA into question.

In addition to seeking to repeal and replace the ACA the Trump administration has made serval attempts to alter legislation and policy aimed at protecting people with disabilities. The 2017 legislation known as HR 620 changed how people with disabilities could request accommodations. The Department of Education under Trump appointee Betsy Devos has made it more difficult for students with disabilities to receive services through school. In March 2019 the Department of Education sough to eliminate funding for the Special Olympics and other funds set aside for students with intellectual disabilities. The Trump administration has created an atmosphere of uncertainty and fear for the disability community in so much of its legislation.

The bill would force a disabled person to first file a notice that usually requires counsel, wait 60 days for a response and wait 120 more days to see if progress is made on remedying a violation of the law before the issue can be brought to the courts. It's intended to prevent frivolous lawsuits against retailers. However, the Center for American Progress found that a recent uptick in ADA lawsuits is not widespread and it stems from a single law firm. Republicans can easily patch up the law to deter profiteering lawyers while maintaining civil rights protections. But they have chosen to take a drastic measure that would make it even harder for disabled Americans to stand up for their rights. Members of the Trump administration have also been punishing disabled Americans.

Last year, Trump's Education Secretary Betsy DeVos rescinded 72 guidance documents that detailed the rights of special needs students. The rescinded documents were created to clarify how federal disability rights law should apply to the nation's school districts. Last December, US Attorney General Jeff Sessions rescinded two dozen guidance documents including several clarifying the implications of the ADA. By doing so, Sessions undermined an Obama-era guidance preventing unnecessary segregation of settings in workplaces as well as vocation and day programs (Das, 2018, para.6-9).

While many of the Trump administration's attempts to weaken protections for Americans with disabilities as created uncertainty it is not the administration alone that makes life difficult for people with disabilities, the perceptions and attitudes of the general public can be as painful as difficult as what has come from the administration.

The people

Josie Badger is thirty-one years old. She has a doctorate in healthcare ethics and holds down three jobs, she has to be careful how much money she makes because if she makes too much, she will lose her funding for the round the clock assistance she needs because of her disability. Josie must stay under the federal poverty line to retain her Social Security benefits that provide for her care. She must choose between being financially independent and receiving the medical care she needs to function on a daily basis. "Under this system, you can have a disability, or you can have a job, but you can't have both," she said (Belser, 2015, para. 4).

Sherry Clair was at the check-out of a local grocery store when the cashier glanced sideways at her son and said "I bet you wish you had known before he came out.

You know they have a test for that now" (Clair, 2014, para. 5). Clair's son has Down's syndrome; she described her shock and bewilderment that someone would say something like that her. Her response to the cashier, born out of frustration, was "I know right?! It's so much harder to get rid of them once they come out. Believe *me* [emphasis hers] I've tried… Jackpot! Her mouth dropped open, and she stared at me in shock" (para 5). Clair goes on to describe how she feels people see her family – as parents and a sister burdened by a child with a disability. Why, she wonders is her child seen as a burden, even disposable, because his mind and body are not the same as an able-bodied child.

D'Anthony White came out to his car from getting groceries to find a note on his car saying, "The only thing hadicap [sic] on you is your brain you lazy NIGGER [capitalization is direct replication of note]" (Fogarty, 2015, para. 4). White is legally blind and has a disabled parking placard to legally use disabled parking spots. He says that because he does not use a guide dog or white cane, people often assume he does not have a disability and are often cruel or deliberately discriminatory (Fogarty, 2015).

Once on her way into the store without her daughter, who requires a wheelchair for mobility, Jamie Davis Smith stopped an able-bodied man as he parked in a disabled parking spot. She explained to him the purpose and necessity of leaving such spots free. "He listened very politely, said he understood completely, then assured me he wouldn't be more than 15 minutes and was running late so he just couldn't be bothered to move his car" (Davis Smith, 2014, para. 9). The story of each of these individuals is intrinsically tied to the historical treatment of people with disabilities, especially in the United States.

Living with a disability in present day America

      Among disability organizations working on inclusion during the last several years there has been a more visible push to increase the number of workers with disabilities and include them in almost every job market (Mank, 2015); just recently the National Organization for Disability (NOD) mentioned that the discretionary funds of the "disability marketplace totals $220 billion – find out how your company can garner the loyalty of consumers with disabilities" (National Organization for Disability, 2015). Still people with disabilities have difficulty affording basic needs care or marrying (Evans, 2015, Jenkins, 2015). How can there be gaps in the policy put forth by public entities like NOD, the laws that govern Social Security Disability (which affect both employment and marriage opportunities) and the public treatment of people like Jeffery Pfeffer, Josie Badger or Sherry Sinclair's child? How is that the ADA had such great potential but then ended up with no real meaning or means of enforcement?

      The answer to such questions may be in how the average person perceives an individual with disabilities. Leadership coach Barton Cutter sees the issue of perception as encompassing three points 1) Avoidance/Rejection, 2) Marginalization/Patronization, 3) Acceptance (Cutter, 2015). As well as being a leadership coach Cutter has Cerebral Palsy (CP). He uses a wheelchair and has what he calls his "thick cerebral palsy accent". When focusing on coaching Cutter "help[s] others dive deep into the lens of their perceptions, breaking down invisible barriers that prevent them from living full and successful lives. Yet as a person with a disability "the lens of perception is a concept I keep in the forefront of my life" (para. 5-6). It is through that worldview that Cutter

explains his concepts of Avoidance/Rejection, Marginalization/Patronization and Acceptance.

He says most people do not know how to interact with someone who has a disability; most of the time people assume that because he has CP, he "didn't have all [his] marbles" (Cutter, 2015, para. 3). The uncertainty of how to engage and sometimes-awkward interactions lead to avoidance and avoidance leads to rejection. The rejection leads to marginalization and patronization, people with disabilities are seen as less than human people because they are viewed as "not normal". Cutter goes on to say that people tend to accept like individuals – that is people with whom we have a life experience much like our own. The average American may struggle with how to relate to what life with a disability is like, so people with disabilities lack acceptance.

Another factor that may affect the perception of people with disabilities is the way people are encouraged to perceive them. The history of people disabilities is discussed more in the rationale, but for the vast majority of American history people living with a disability have been viewed through the medical model. The medical model is one where people are seen as broken and need repaired (Withers, 2012). Feminist theory Sandra Bem called it "androcentrism" (1993). According to Bem both medical views of normalcy and equal rights laws were based in ideas about physically ideal white males dating as far back as ancient Greek and Roman societies. Anyone who did not fit this description was considered deviant or abnormal and therefore not worthy of equal protection under the law.

When Perception Leads to Marginalization

Drabek's (2014) arguments from a sociological standpoint support Cutter's (2015) observation. There are several types of marginalization he mentions. Pressive – where members of groups labeled as subordinate are forced to serve dominant groups. Nielsen (2012) argues it is not as common now as it once was for people with disabilities to serve abled-bodied people. However, there are those who would argue that labeling people living with a disability as "inspirational" is a pressive form of marginalization Young (2014) and puts them in a sort or servile role. Additional forms of marginalization as Drabek sees them are expulsive, dismissive, and preservative.

In expulsive marginalization, members of the subordinate group (people living with a disability) are driven out of the community. Nielsen (2012) points to the forced institutionalization and sterilization of people living with a disability throughout American history. Dismissive marginalization pushes unwanted members to the edges of society. Physically being unable to access the public sphere can push people with disabilities to the margins of society. Preservative marginalization is when the dominated group (able-bodied) uses a subordinate group (disabled) to preserve the dominant group's sense of normalcy. Young (2014) says if disability were removed from the equation then there would be no difference and therefore no inspiration. What is so powerful about Drabek's (2014) observations on marginalization is that often groups are labeled as marginalized and people recognize that, but they do not recognize that in reality it is their own practices and activities that marginalize others.

Marginalization and the Effects on Group Behavior

Once a group has experienced marginalization through the activities and practices of others, breaking free of the mentality of marginalization can be difficult. In the case of people with disabilities marginalization can lead to internalized ableism, shame and isolation. Isolation can be either self-imposed or due to societal barriers that prevent them from being out in public. The isolations keep them from participating in their community, which furthers the oppression because they are not able to publicly address lack of accessible community spaces.

To surmount the situation of oppression, people must first recognize its causes, so that through transforming action they can create a new situation…Although the situation of oppression is dehumanized and dehumanizing in totality affecting both the oppressors and those they oppress, it is the latter who must, from their stifled humanity, wage for both the struggle for fuller humanity; the oppressor who is dehumanized himself because he dehumanizes others, is unable to lead this struggle.

However, the oppressed have adapted to the structure of the domination in which they are immersed, and have become resigned to it, are inhibited from waging the struggle for freedom so long as they feel incapable of running the risks it requires. Moreover, their struggle for freedom threatens not only the oppressor, but also their own oppressed comrades who are fearful of greater repression (Freire, 2009, p. 47).

Internalized oppression David (2014) says is the idea that the oppression a group receives is deserved because the oppressed group is made to feel so through systematic, institutional oppression. It comes from all sides and in all ways, even from those who are well meaning with the best of intentions. From a psychological standpoint David

believes that internalized oppression leads to debilitating depression, shorter life spans and decreased quality of life. Watermeyer and Görgens (2014) point out that people with disabilities find internalized oppression occurs because it is still socially acceptable to marginalize people living with disabilities. "So embedded is the cultural idealization of bodily normalcy and vitality, that disability prejudice is not the premise of a bigoted few, but a pervasive, unspoken, and intrinsic social reality" (p.274).

Charlton (1998) vocalized these very concerns years ago, eight years after ADA was enacted into law he said, "Our community's history of isolation, degradation, dependency, medicalization, and discrimination has created an internalized alienation of self-pity and inferiority" (p.75). The fact that Watermeyer and Görgens (2014) are repeating Charlton's admonition in 2014 means there is still much work to do and progress to be made on every level for the equality of people with disabilities.

There is no simplistic way to define disability or what it means to live with one. While Charlton (1998), Drabek (2014), and Watermeyer and Görgens (2014), may all be correct about the treatment of people living with disabilities. The reality is living with a disability is complex. Multiple life factors must be accounted for and improved for the treatment of people living with disabilities to improve.

Purpose and Goals of the Dissertation

With laws in place that are supposed to support people living with disabilities, there are still questions that remain. Why does having a disability still make someone an easy target for mistreatment or even legally sanctioned discrimination? I have my own stories of mistreatment and discrimination, as does virtually every author I found who has written about disability issues; those who have opted to deal with disabilities in the Ph.D.

dissertations are not exempt (Auterman, 2011; Knight, 2013; Nielsen, 2012; Owen, 2011; Withers, 2012). It is not just the lived experiences of people with disabilities that point to the disparity of their treatment by individuals and systems within the United States.

The legal policies, educational and employment opportunities, medical treatment and even media representations of people with disabilities contribute to continued marginalization of the largest minority in the world (WHO, 2011). In 2010 President Obama signed "Rosa's law". It was a law that changed the wording in all-federal health, education, and labor laws, instead of using the phrase "mentally retarded" with references to "intellectual disability". In a transcript provided by the White House of the President's signing of the 21st Century Communications and Video Accessibility Act of 2010, President Obama praised Rosa's brother Nick for his vocal support of his sister and of changing the law. President Obama said:

> I want everybody to hear Nick's wisdom here. He said, 'What you call people is how you treat them. If we change the words, maybe it will be the start of a new attitude towards people with disabilities.' That's a lot of wisdom from Nick. (Whitehouse.gov, 2010, para.11).

In Marshall Rosenberg's *Nonviolent Communication*, he tells the story of hearing the word "Kike" for the first time and the resulting violence that ensued. It was the fall of 1943 after the race riots in Detroit, Michigan and Rosenberg's name was called for class attendance. Two boys asked, "if I was a Kike…after school the same to boys were waiting for me: they threw me to the ground and kicked and beat me" (Rosenberg, 2015, p. 2). Rosenberg goes on to discuss how the language we use can increase or decrease the risk of violent communication. There is potentially strong correlation between the

claims that Rosenberg is making and the treatment of people with disabilities, particularly when it comes to the impact of language on structural violence.

The purpose of the dissertation is to explore the role of language and attitudes in the continued marginalization of people with disabilities. The first goal of this dissertation is to inform the public of the state of the disabled population in the nation, of the minority groups and social movements that have made progress in the rights area and have gained public acceptance as contributing members of society in this country, people with disabilities are still the furthest behind and most overlooked (Johnson, 2003; Pfeffer, 2015). Watermeyer and Görgens, (2014) have acknowledged that most people do not even see people with disabilities as a minority in need of attention (p. 253). Their point is a valid one.

During a 2015 change.org campaign both the Pew Institute for Research and The Center for American Progress were petitioned to include disability as a demographic included in their research. The Center for American Progress agreed to create a tag for that demographic, the Pew Research Center, one of the largest research organizations both nationally and internationally, refused to respond to the petition and they do not list disability as one of the areas they research (Change.org, 2015). A second goal is to investigate the areas in the public sphere where people with disabilities are still struggling to gain the same kind of acceptance as able-bodied counter parts. A third goal is to recommend actions that would increase the visibility and acceptance of people with disabilities in the public sphere. Additionally, there is ample room for conflict resolution practitioners to help better include people living with disabilities in our society.

Conflict Studies Perspectives

There have been many different groups who have contributed to disability rights, policy and awareness (Vaughn Switzer, 2003). It is worth exploring what role conflict resolution practices can play in helping people with disabilities find inclusion and acceptance in society. Many conflict resolution practitioners, particularly the authors of the widely accepted mediation models that seem to dominate the field (Bush & Folger, 2005; Moore, 2003; (Winslade & Monk, 2000) strongly advise neutrality in dealing with conflict.

When neutrality won't work. Most conflict studies scholars advocate self-determination as a corner stone to conflict resolution and therefore the practitioner should be a neutral guide only helping to balance the power of both parties (Bush & Folger, 2005; Winslade & Monk, 2000). The problem with this line of thinking is that it poses several stumbling blocks for the disabled community. The first is that there is a severe power imbalance, when the discrimination runs as deep in society as Watermeyer and Görgens (2014) claim and the individual stories attest to, then the conflict practitioners' job is to balance the power. There is nothing neutral in that act.

The second issue is that most people regardless of disability status lack the listening, negotiating and conversational skills in which conflict practitioners are trained. Mayer (2004) encourages and advocates conflict practitioners moving past neutrality and using their skills to help others achieve their goals. "Advocates are essential to the functioning of conflict. Good advocates are skilled in conflict engagement: raising conflict, negotiating and resolving conflict" (p. 248). He says if conflict practitioners are willing to be the right kind of advocate – an advocate to help in

affective conflict then by all means embrace the role of advocate. Kenneth Cloke (2001, 2008) has also been a proponent of conflict practitioners engaging in conflict in such a way as to change political landscapes.

Political conflicts have grown so costly, destructive and global that there really is no alternative, either as citizens or conflict resolution practitioners, then to summon our courage, evaluate what we can contribute and do what we can to ease the world's suffering (Cloke, 2008, p. 86).

He says we must be willing to face fear and apathy if we hope to see change for individuals or societies. Here again current scholars are echoing their counterparts from the first wave of responses to ADA. Majiet (1996) specifically issued a call to women with disabilities to rise up and advocate for their identity and needs as their own, and to determine to do so despite the fears that they may have about doing so. Her call to action, like Pfeffer (2015), says should apply to everyone. For practitioners concerned about jumping head first into the deep end of the advocacy pool, Gelak (2008) offers a reminder that advocacy takes many forms from research to testifying before Congress as an expert in a given field; in this case in the conflict created by the impact of policy and perception of people with disabilities. Ury (1993) has been inviting negotiators to go to the balcony and build people golden bridges for a long time. There is nothing that would prevent conflict resolution practitioners from helping the disability community achieve their goals through these means.

The paradoxes: Bernard Mayer (2015) has identified seven paradoxes in our cultures that he believes lead to conflict. Three of his seven paradoxes hold particular

saliency for the disability community in terms of conflict resolution practitioners and perspectives.

The first is the idea of advocacy and neutrality, here again Mayer (2015) points to the fact that self-determination is dependent to a certain degree on others' willingness to advocate with and for the people who turn to conflict practitioners for help. "Our work as interveners requires that we learn to function both as advocates and neutrals to fulfill our commitment to our clients and to promote a constructive end to conflict" (p.202). Both Cloke (2001) and Mayer have made it clear that it is vital conflict practitioners engage in politics and power balancing. This idea also feeds the second of Mayer's paradoxes, avoidance and engagement. From a disability perspective like Cutter's (2015) and Drabek's (2014) where lack of engagement on the part of the more powerful party leads to avoidance of the other party (people living with a disability). From Mayer's perspective how we avoid or engage in conflict determines the conflict's outcome. Here is where Cutter's and Drabek's perspective merge with Freire's (2009) Cloke's (2001) and Mayer's, if fear, oppression, and apathy are driving the avoidance in dealing with the status of people with disabilities, then it is much harder to engage both people with disabilities and the policies that have such a powerful impact on their lives.

Mayer's (2015) third paradox is the most important for the disability community. It is the conflict autonomy and community. Mayer discusses the need for people to be independent and autonomous while also having the need to be a part of a community, and that often those two needs conflict with each other. The irony for people with disabilities is that they need the support of a community that has pushed them to the margins (Cutter,

2015; Drabek, 2014; Pfeffer, 2015; Watermeyer & Görgens, 2014), to gain autonomy and be able to fully engage in both an individual life and active part of the community.

Naomi Ortiz (2015) says the ability to be independent and be part of a community is a relationship issue that takes interdependence to make the autonomy/community paradox work. In a blog post on the subject Ortiz says:

The Disability community has worked hard to reject what society teaches, that disability access is a personal problem. The Disability community instead puts forth that Disability is a social and political issue. And yet, either perspective our friends understand can create a problem in them in considering what their responsibility to us is. When we think of access as a personal problem, then it is the Disabled person's problem to figure access out. When we view access as a political and social issue, then we view it as "out there", something that needs to be addressed by laws or organizations. Disability in essence is a relationship issue. This is because we are actually unable to live our lives fully on our own. (We could argue no one can make it on their own, but Disabled people can't usually "fake it" as well) (Ortiz, 2015, para. 17-18).

Another relevant conflict perspective is that of functioning systems. Page (2007) argues that diversity in a system like society is key to the success of those societies and their participation in it, but if a group's ability to participate in the society is hampered then both the group and society suffer. He says that fully functioning diversity must be a priority for us, but it cannot occur until we invite and create the means for those on the margins of society to fully participate. At present the disability community cannot fully

participate because the policies and perceptions in our society are preventing that from

occurring (Cutter, 2015; Drabek; 2014; Ortiz, 2015; Watermeyer & Görgens, 2014).

A valuable piece of research and practice that has recently been introduced in the

public sphere is the idea of strategic negotiation that is relevant to the study is strategic

negotiation (Feingold, 2016). Strategic negotiation is a technique that uses negotiation as

a way to further the ADA compliance that circumvents the traditional ADA lawsuit

approach. A seven-stage process that recognizes the language surrounding disability is as

important to the outcome of the negotiation as the settlement. Feingold's approach while

not new has taken on a heightened importance with the increasing public awareness of

ADA lawsuits and the potential loss of care and benefits for people with disabilities under

the Trump administration. A strategic negotiation approach would benefit both

businesses and consumers with disabilities in two ways. The first is that it helps to

reduce the adversarial experience that current ADA laws create. Feingold points out that

consumers with disabilities are suing companies to get access because that is what they

are told they have to do. The patrons, she points out, want to be able to shop at or

interact with business not make life difficult for the businesses.

The second way strategic negotiation would assist with accessibility is that it

leaves room for negotiating settlements that can be customized for both the

businesses. In the book she discusses working with a national movie chain to provide

audio description for blind patrons. While the chain didn't have the money to implement

the changes immediately nationwide, they were able to provide the service in the region

of local theaters where the complaint originated.

The Power of Community Online and the politics of dis-citizenship

One way in which the disability community is pushing to participate in changing both policy and perception is by taking political activism and community building online. Doing so is a way of combating the concept that "dis-citizenship". In discussing critical disability theory Pothier and Devlin (2006) use the phrase "dis-citizenship" as a way of describing how disabled people are prevented from practicing citizenship in a way that not only gives them status of belong to a recognized state entities, but allows them to practice citizenship in its fullest capacity. "We want to suggest that because many persons with disabilities are denied formal and/or substantive citizenship, they are assigned to the status of 'dis-citizens', a form of citizenship minus, a disabling citizenship" (p. 3). The idea that disabled citizens lack full participation as citizens, particularly as collective or individual or political bodies, was one of the issues that the ADA was meant to address but it has done an inadequate from job of fostering such participation. Using social media as a form of political activity and community building is something that grown as the internet's capacity and usability has spread especially to the disabled citizenry.

> Internet accessibility (Ellcessor, 2016) and the cost of connection has been falling at a staggeringly fast pace (international telecommunications union 2012), making access not only more affordable but at the same time also more relevant to disabled people. As a result, a majority of respondents in recent surveys on Internet use in the both the U.K (Dutton & Blank 2013) and the U.S. (Fox 2011) defined themselves as regular internet users (Trevisan, 2017, p. 3).

Trevisan's (2017) focus was on the use of Facebook as a tool for political community activism among disabled citizens in the U.K, but the study drew significant comparisons with such groups inside the United States. While he found that the groups used Facebook to somewhat different ends his research indicates that Facebook can be a powerful tool for disabled citizens to actively participate in political movements and feel affirmed while doing so.

Other research also has supported the idea that technology is helping disabled citizens to not only engage where they might now have otherwise previously engaged, but build relationships in the process (Gad, Ramakrishnan, Hampton, & Kavanaugh, 2012) said:

> In the past structural constraints internal to disadvantaged communities limited opportunities for deliberation and democratic participation. Social technologies may make communication possible where it was not before. One possible explanation, as to why social media may be such an important tool for engagement among this population, may relate to the way these technologies bring people together (pp. 173-174).

Another social media platform that is used by disability advocates and educators is Twitter. Trevisan's research suggest that rapid response and high technology aptitude and limited character response may limited typical disabled people from using the platform, but other people say Twitter is an important social media tool for connection and participation in political and educational activities related to disability. Robin Wilson-Beattie is a sex education instructor who focuses her work primarily within the disability community. She uses Twitter as a main source of connecting to those she for

whom is trying to educate and advocate. While discussing Twitter at a conference

Wilson-Beattie said:

> Twitter has actually really become a critical digital platform for advocates and
>
> activists in many social justice movements to share thoughts and ideas, and
>
> events, and to participate in actions related to their cause. It's free. It's accessible.
>
> And it allows people to publicly disseminate their thoughts, information, and their
>
> news really quickly and really efficiently. What makes Twitter particularly unique
>
> in the social media sphere is the very open and public way that people are able to
>
> connect around the world and have unparalleled access to organizations,
>
> businesses, public officials and figures. Like, you connect with people really
>
> quickly, really openly, in a way that you can't connect sometimes with a phone
>
> call or writing a letter. So why is Twitter an ideal platform, though, for disability
>
> advocates and activists who want to create change in their communities? And like
>
> I mentioned, first off it is free! And one barrier to access that people with
>
> disabilities face are economic. Across the world, people with disabilities have less
>
> economic participation and higher rates of poverty than people without
>
> disabilities, and this is partly because people with disabilities experience barriers
>
> in accessing services that many able-bodied people take for granted, including
>
> health, education, employment, and transportation. As well as information. And
>
> these difficulties are even more exacerbated in less-advantaged communities
>
> (Wilson-Beattie, 2018, para. 5-7).

Gad et al., (2012), Trevisan (2017) and Wilson-Beattie 2018 all mention that

physical barriers and economic disadvantage contribute to "dis-citizenship" and for this

reason Trevisan says that further research on the impact of social media in the ability of disabled citizens to participate in substantive engagement should be further studied alongside traditional forms of access and inclusion. Studies he said should contribute "to a fuller and more nuanced understanding of the complex relationship between disability and the internet as well as a way of determining the position of disabled people in today's fast-changing techno-political environment" (p. 3).

The invitation to have studies further contribute to a "fuller and more nuanced" understanding of disability is something this study aims to do. With increasing acknowledgement that disability is both complex and underrepresented, there needs to be more research done around aspects of disability that make room for the wholeness of disability not just the medical aspects that can be treated, fixed, or cured. There is more to disability than what is represented in the media or in legal terms of accommodations, and yet so much of the research is from a single perspective that focuses on narrow aspects of disability that such research contributes only in part, this research provides a larger perspective on disability in America.

Rationale

People with disabilities face discrimination and difficulty in every aspect of public life and anyone has the potential to experience disability in their lifetime (World Health Organization [WHO], 2011). The results from a 2010 survey done by the U.S. Census Bureau (Brault, 2012) show that 56.7 million people or nineteen percent of the population reported having a disability, of those people ages sixteen to sixty-four report a forty-nine percent unemployment rating and those that did work reported income well below the federal poverty level.

Inclusion of people with disabilities as valuable members of society is even difficult to find in the media. Fox's Glee featured an actress with Down syndrome, but her story lines were often as questionable as they were controversial. Her story lines included her being responsible for bringing a gun to school (Diament, 2013). Advocates called the story line a "poor choice", others were more vocal "Thank you Glee for setting Down Syndrome awareness and acceptance back light years. Some people now see our kids in an even worse light," wrote one viewer known as T21ASDMommy on Twitter" (para.9). Perceptions of people with disabilities fall into seven categories according to Vaughn Switzer (2003) 1) Pitiable and pathetic – they are victims of their own circumstances and bodies. 2) The Super Crip, an inspiration to able-bodied people. This is the image that Young (2014) speaks out against and by Drabek's (2014) standards is a form of marginalization. 3) Sinister, evil and villainous – Fox's Glee perpetuated this stereotype with the school shooting storyline. It promotes the idea that people with disabilities should be feared. Such assumptions contribute to marginalization (Drabek, 2014; Freire 2009). 4) Better off dead – the cost and frustration of living with or caring for someone with a disability means it would be better if they were dead than disabled. 5) The bitter, maladjusted person – if people living with a disability would look on the bright side of their impairment as realize "it could be worse" so be grateful you do not have or are not like someone with a worse disability. 6) The burden – this was what Sherry Clair thinks people see when they see her family. That caring for or living with a disability is an emotional and financial burden – and therefore the people living with a disability would be better off dead for everyone's sake. 7) Not able to be successful at life – this portrayal is not is what is present – it is what is missing. That is there are few

to no representations of people living with a disability living what society considers "normal lives" in the media. The absence of these representations implies it is not possible for people living with disabilities to have normal lives.

The goal of the research must be tailored to examining the complexity of the relationship between the language, the policy and the perceptions we use to discuss disability and the full inclusion of people living with a disability in American society particularly in relation to the social media platform Facebook.

The Role of Critical Auto-Ethnography

Mertens (2009, 2015) openly advocates for researchers with disabilities including their experience as part of the research perspective. Originally the degree to which auto-ethnography was to be included in this study was minimal, however a permanent change in health status made in the inclusion of auto-ethnographic experiences unavoidable as the degree to which my experiences with disability began to mirror the research in earnest.

Madison Soyini's *Critical Ethnography: Methods, Ethics, and Performance* is a guiding source for navigating the role and purpose of critical auto-ethnography in this research. The power that lies within critical ethnography for researchers with disabilities cannot be ignored. She calls on critical ethnographers to "resist domestication". She, like Mertens (2009, 2015), says that research is meant to be "emancipatory" and that critical the ethnographer must

> [U]se the resources, skills, and privilege available to her to make accessible - to penetrate the borders and break through the confines in defense of - the voices and experiences of subjects whose stories are otherwise restrained and out of

reach...We now begin to probe other possibilities that will challenge institutions, regimes of knowledge, and social practices that limit choices, constrain meaning, and denigrate identities and communities (p. 6).

In light of that parallels between my life and the research it is necessary to address my own critical auto-ethnographic influences and fully acknowledge membership in the research group, and my purposes in advocating for the very aspects of the research Soyini mentions above.

Soyini (2012) defines critical ethnography as the ethical responsibility researchers have to address "unfairness or injustice in a lived domain" (p. 5). The critical ethnographer Soyini says is obligated to do research in a way that calls out inequity and demeans change. "The critical ethnographer also takes us beneath surface appearances, disrupts the status quo, and unsettles both neutrality and taken-for-granted assumptions by bringing to light underlying and obscure operations of power and control" (p. 6). Soyini also argues that reflection is a vital part of critical ethnography.

Researchers must always acknowledge positions of "power, privilege and bias" according to Soyini and yet must also recognize that "belonging precedes being". This means that I must acknowledge that as the researcher I have certain privileges that come with that position while simultaneously recognizing that my belonging to the disability community in many ways precedes and impacts my being a researcher. As researcher with a disability I am uniquely positioned to be reflexive about the study and my unique position to said research while directly engaging in the research as means addressing gross inequity in the lived experience of disability in America.

In addition to calling for critical ethnography to assist in the pursuit of equity and calling on researchers to be reflexive Soyini (2012) advises on several other issues that have direct impact on this research. On the issue of language, she says that language and its subject are deeply connected, particularly how language relates to the concept of desire, with desire not being a solely sexual concept here. Language helps to

[A]ddress (a) the question of how language, in this case narration, [in the case of

my research content analysis], orders and conceptualizes one's very being; (b)

how language forms and discovers experience by making unknown now known

and manifest; (c) how the need expressed in the telling is beyond sexual need,

how [people] experienced the human and universal need for recognition; and (d)

how our needs are compounded into a desire to reveal our true selves, particularly

by the added need of not wanting to experience rejection (Soyini, 2012, p. 75).

Her musings on language provide direction in how to examine language as one of the key components, not only of the study, but in the framing of the disabled experience.

A second relevant issue that Soyini (2012) covers is the ethics of advocacy. She affirms that it is a researchers' ethical responsibility to cover the distance between "'what is' and 'what ought to be' (p.97). Advocacy through research is the ethically appropriate and responsible action that should be taking place, especially when research notes that inequity exists. Critical ethnography she says is the act of bearing witness, "and in bearing witness I do not have the singular 'response-ability' for what I witness but the responsibility of invoking a response-ability in what was seen, heard, learned, felt, and done in the field and through performance" (p. 97). Our shared and compelled morality

she says requires us to advocate in and through our research for the creation of a better world, from such a perspective this study is as much advocacy then as research.

A final area that Soyini (2012) provides context for the study is through the examination of what she calls "social performances". Social performances are the ethnographic study of everyday life. These differ from highly scripted ritual activities that might take place in a culture such as a wedding or a funeral. The acknowledgement that social performance are "examples of a culture's or subculture's symbolic practices" (p. 171) is important because it helps give a foundation for disability as a subculture whose social performances are concurrently the same and profoundly different than their able-bodied counterparts in the same culture; such practices Soyini says include "dressing, dating, walking, and looking" (p. 171). How people with disabilities do the social performances of dressing dating, "walking" and looking have a direct impact on the perceptions and policies that affect them, which is not necessarily true with able-bodied people.

Study Reflections and Ethics Concerns

In reflecting on the study and its ethical concerns there are at least two issues that could be considered cause for apprehension. The first is that I, as the study's author, have a disability. For many this would be immediate cause to claim the study is both unfairly biased and inherently invalid. However, after spending a great deal of time with Mertens materials (2009, 2015), I have come to see my disability as an asset to the study, not a hindrance to it.

One of the key aspects of transformative methodology and evaluation according to Mertens (2009, 2015) is that the voice and input of the population being studied must

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be a palpable part of the study. She says that population must have a say in the study and that it is perfectly acceptable for transformative researchers to engage in auto-ethnography. If it is warranted I certainly would, however, by focusing on language usage I believe the study will give better voice and understanding to some universal experiences of living with a disability regardless of what the disability may be.

The other cause for concern that I have as the study's author is the lack of direct input from the disability community in terms of responses to surveys or focus groups or more traditional data gathering tools. My purposes in avoiding the direct participation of individuals with disabilities are based in IRB restrictions. Since the IRB requires careful consideration of vulnerable populations, it makes working with people with disabilities beside myself that much more complex. Because I feel representation of all disabilities is important, I am not willing to leave intellectually disabilities out of the study. This would be difficult to do anyway because in many cases physical disabilities and intellectual disabilities accompany one another, and the language use surrounding intellectual disabilities is just as important as the language usage surrounding physical disabilities and mental health. (Both intellectual disabilities and mental health materials will be included in the study because they are covered in ADA legislation). If there is a way to incorporate the disability community in the study as well as the general public that would be acceptable to the IRB, I would be open to adjusting the research accordingly.

The ability for people in the conflict resolution community to contribute to the inclusion of people with disabilities into the greater community is deeply needed. As is this study on the language we use in regard to disability. How we talk about disability impacts every aspect of life with a disability and that has a powerful impact on how

people with disabilities are treated.   As recently as 2016, people with disabilities became part of the U.S. Presidential Election when Donald J. Trump openly mocked a reporter with arthrogryposis at a Trump campaign rally. While the incident was widely condemned, however spoke to the larger issues of how people with disabilities are perceived in the public sphere. Arlene Mayerson, Directing Attorney for the Disability Rights Education and Defense Fund says that Trump's mocking of Serge Kovaleski hit a nerve with general public because the disabled community has always been seen as "off limits" for public mockery (Mayerson, 2016). Mayerson said she was concerned that people do not seem to be "making the policy connections about this the way we do for racist and sexist comments" (para. 3). She continued saying:

> Trump's mocking of Serge's disability is not only about incivility and bullying, which are bad enough. These attitudes about disability, result in a backlash against the political struggle for equal rights and dignity of people with disability (Mayerson, 2016, para. 6).

In her article Mayerson (2016) points out that she first made the arguments connecting public perception and policy about people with disabilities in a legal brief she wrote in 1984. While perception of people living with disabilities is influenced in many ways Kramarae (1981) has proven that language is one of the most powerful tools in efforts to include or exclude non-dominant groups. It is time to look at the impact of language on the inclusion of people living with disabilities.

Chapter 2: Literature Review

Theories and Frameworks

There are several theories and conceptual frameworks that help provide insight into the issues of perception surrounding people living with disabilities. The first theory is muted group theory. According to Griffin (2009) a muted group is defined as "People with little power who have trouble giving voice to their perceptions because they must re-encode their thoughts to make them understood in the public sphere" (p. 455). Cheris Kramarae is the author of muted group theory.

Muted Group Theory

In her work *Women and Men Speaking,* Kramarae (1981) established seven hypotheses with regard to the way men and women express themselves in public. It is Kramarae's contention that as a non-dominant group woman lack the power to influence the language, which they are allowed to use, and the language, which is used to refer to them in the public sphere. Of the seven hypotheses, three have a considerable impact when discussing people living with disabilities as a muted group.

The first hypothesis that has application when looking at perception and people living with disabilities is Kramarae's (1981) claim that "Females are more likely to have difficulty expressing themselves fluently within dominant (public) modes of expression" (p. 4). She details that both the verbal and non-verbal communication conventions that women use are outside the dominant conventions created by men and therefore are not as recognized in the public sphere as being acceptable as the communication conventions established by men. Likewise, people living with a disability have difficulty expressing themselves within the conventions established for able-bodied individuals, whether those

conventions are verbal or non-verbal or somehow physically prevent them from engaging all together, such as a blind person attending a movie theater or a deaf person using a drive thru. Being physically excluded from established communication conventions is not the only difficulty faced by people living with disabilities.

Kramarae's (1981) second hypothesis that could apply to people with disabilities is the idea that "Females are not likely to coin words that will become widely recognized and used by both men and women" (p. 4). In other words, the terms used about women and the terms women are allowed to use, are initiated by men as the dominant group and all groups are expected to use the ascribed language. People with disabilities face the same issue.

They are perceived according to the language ascribed to them by the able-bodied dominant group. In many cases that language is derived from the medical model of disability that views the disability as a deficiency or abnormality in need of correction or augmentation (Withers, 2012). In other cases, it is the use of language used to described disability making it is way into popular language to describe people or situations that are undesirable. In particular the word "retarded" has seen use as a descriptor for discomfiting scenarios or people. "The word 'retarded' is also used so casually by some people in day-to-day conversation. You hear people saying it in reference to foolish behavior, music, television, etc. I bet you have heard it used in many different contexts" (Gushue, 2015, para. 2). While there are many like Gushue and Withers willing to speak out about the language that envelops disability whether those with disabilities can successfully mobilize to change perception is worth exploring.

Among Kramarae's (1981) hypotheses was the idea that women, who rejected the perceptions predetermined by the dominant group, would challenge and change the dominant modes of expression with regard to women. There is a persistent movement to change the perceptions of people with disabilities as discussed in the themes found in the literature, such as the move to modernize the universal access symbol (Hendren, 2016) where the wheelchair symbol has been given a sportier active look in hopes of changing people's perceptions of disabilities. The difficulty that faces the disability community is the same difficulty that Kramarae says once faced the Women's Liberation Movement and that is moving their message to a point of dominant group acceptance. It was precisely the lack of non-dominant group acceptance that hampered the literature search strategies.

One significant study that uses muted group theory was Obre's (1996) study looking at what communication strategies non-dominate groups used to communicate with dominant groups. Using the co-cultural communication model, a model which presupposes a clear communication experience because both participants have created a shared cultural. Obre (1996) investigated how non-dominate groups negotiated the creation of that shared culture despite being a traditionally muted group. In addition to muted group theory Obre uses standpoint theory as the foundation for understanding that not all individuals in a like group share similar experiences or perspectives.

In the study Obre (1996) used phenomenological methods to collect and analyze the lived experiences of individuals in non-dominant groups such as women, members of the LGBTQ and African American communities. While mentioned as a non-dominant group Obre did not include people with disabilities in his study. His findings determined

that members of non-dominant groups used three categories of communication methods to negotiate communication experiences: assimilation, accommodation and separation. Each category was then divided into aggressive and non-assertive forms of each of the methods.

Particularly salient to the perception of people with disabilities is a question that Obre (1996) reiterates from previous research on non-dominant groups, that question is "how people function as both the vehicle and the target of oppression" (p. 21). In the spirit of this question Obre attempts to examine this phenomenon through looking strictly at the direct conversational styles adopted by non-dominant group members. It is question worth hanging on to as the perception of disability is further explored particularly through the additional theories and conceptual frameworks discussed throughout this research.

One of the most challenging decisions in the process of looking at perceptions on disability is the act of defining disability. There is a debate today among those who work, study and live in and around disability about how it should be viewed. Many writers and scholars argue chiefly that the "medical model" of disability is one-sided and out dated (Auterman, 2011; Charlton, 1998; Haller, 2010, Waters and Görgens, 2014 and Withers, 2012) and that political, social and identity models ought to be the primary viewpoint for discussing disability (Charlton, 1998; Gerschick, 2000). They make valid points about the intersectionality of identities while at the same time downplaying the need for medical care and technological advancement to increase both quality of life and inclusion for those with disabilities.

Those who lament that the medical model of disability is dehumanizing are right, those who argue that disability is a part of identity are right. The difficulty with the concept of disability is that it has many aspects to consider. Individuals with disabilities will discuss the expenses and lack of opportunities they face in trying to be autonomous (Evans, 2015), they tell of the challenges that come with trying to see everyday life through the constant lens of accessibility and inclusion (Ortiz, 2015). Scholars like Gerschick (2000) and Withers (2012) call for new theories with regard to disability. There is a theory that fits as it affords all the aspects of disability to play an active part in the discussion. Using muted group theory as cornerstone to the study allows us to compare the language used to describe disability in the same way Kramarae looked at gendered language, particularly when it comes to how words are used and who is using certain types of words.

Complexity Theory

In addition to muted group theory, complexity theory provides several significant avenues for investigating the many facets of disability. The first reason that complexity theory is a helpful is that it acknowledges that there are virtually no phenomena that has benefited from a reductionist approach. Disability is certainly no different. Secondly, complexity theory provides a lens to look at connections between seemingly unrelated concepts especially when those concepts are viewed from only one field (Johnson, 2007). With disability then complexity allows for looking at the relationship between medical care, employment, social acceptance and identity, all which studied in isolation would fall under different fields like science, economics, sociology and psychology. Johnson concedes that in general complexity theory is geared toward

looking at systems like financial markets but maintains that "complex human systems"

(p. 97) exist and are in need of study.

According to Johnson (2007) networking is an aspect of particular salience to

human complex systems. Johnson's assertion that networking is an important part of

human complex systems has bearing on the aspects of disability because it melds well

Mayer's (2015) ideas about autonomy versus community and Morgan's (1998) concepts

of cultural complexity. Mayer argues that one of the most potent conflicts that face

human interactions today is the paradox between autonomy versus community. Johnson

maintains that networking, or human connections, is one of the most complex part of

human interaction. Cutter (2015), Evans (2015) Ortiz (2015), and the National

Organization for Disability (NOD, 2015) argue that networking is vital part to building

communities that empower people with disabilities to be both autonomous individuals

and active community members.

Using Morgan's (1998) concepts of cultural complexity in addition to Johnson

(2007) and Mayer (2015) helps to further appreciate the complicated nature of defining

disability. He says, "the concept of culture signifies that different groups of people have

different ways of life" (p. 113). Living with a disability is certainly a different way of

life that has its own "knowledge, ideology, values, laws, and day-to-day ritual" (p. 112).

Critical Disability Theory

The two concepts that are the foundation are power and context. Pothier and

Devlin (2006) says that critical disability examines who has power, who does not have

power, and who gets marginalized because of lack of power. Context in that disability is

not just impairment but includes social values and institutional preference - or lack

thereof.   The intent of critical disability theory is to examine systems of politics and justice that are built around the lives of disabled people as integral to the process of justice and equality, not as a secondary to it. Pothier and Devlin maintain that current systems are "just us" systems that marginalize people with disabilities and create an "us and them" dichotomy where as critical disability theory "emerges from the bottom up, from the lived experience of persons with disabilities, rather than from the top down" (p. 9). Equality is also an underpinning of the theory in terms of human rights and the theory rejects the hierarchy that places disability in the realm of abnormality.

Critical disability theory is built around four themes: (1) language, definitions and voice, (2) contextual politics and the politics of responsibility and accountability, (3) philosophical challenges, and (4) citizenship/dis-citizenship. The theory's acknowledgement that language can shape not only the identity of people with disabilities, but policy that affects them is paramount to the study's understanding of language as one of its components. CDT also recognizes that the definitions of disability can alter the context under which legal and social services are rendered or denied. What is more is CDT incorporates the voice, the empowerment, of disabled people which is rare in a theory.

Contextual politics and the politics of responsibility and accountability, the second tenet of the theory comes from the failure of liberalism to "pursue substantive equality" (p. 9) because while it seeks to maintain a hierarchy of difference by maintaining the idea that disability is the epitome of "suffering". The theory is the "pursuit of empowerment and substantive, not just formal, equality" (p. 8). It goes

further to say that the combination of neo-liberalism and globalization has just further

marginalized people with disabilities.

The philosophical challenges that the theory addresses are those that they see as

the reasons for the marginalization of disabled people. First is pervasiveness of ableism

that people with disabilities face from both society and institutions - even the ones meant

to protect their rights, second is intersectionality, if a person is disabled and black or a

black, disabled female then their chances of experiencing discrimination become three-

fold. In such cases it becomes hard to determine where the discrimination based on

disability begins or ends in comparison to the other factors. Third is the concept of

passing as a viable option for those with disabilities who can. Because marginalization is

likely to be faced by people with disabilities, passing is reality that many engage in

whether intentionally or not, because they are so accustomed to trying to accommodate

those around them instead of vice versa.

Citizenship/Dis-Citizenship is the final tenet of the theory. The theory posits that

disabled people are not given the opportunity to have full citizenship. In multiple

countries disability is an immediate disqualifier for immigration. Capacity for

productivity is also intricately tied to citizenship Pothier and Devlin (2006), "we detect

even in this literature the tendency to assume that genuine citizenship entails a capacity

for productivity, and that if one cannot be productive, one is not worthy of full

citizenship" (p. 17). As such the theory calls for expanded definitions of citizenship,

definitions that do not rely on a disabled person's productivity to qualify them for full

citizenship. Each tenet of critical disability theory provides clarity to much of the

complexity that surrounds disability. Critical disability theory helps to fill in the gaps left by muted-group and complexity theory.

Perception and disability

Of the material reviewed multiple studies provided pertinent evidence to the support the study of language as it pertains to attitudes and policies about people with disabilities four of the studies dealt with the impact of current theories applied to disability or people with disabilities. Two studies were meta-analysis studies that both suggested specific measurement tools that might prove useful in the research phase. Another study useful for the research evaluates language used to describe people with disabilities in Poland versus the United States. One study examined the attitudes surrounding the acceptance of an individual with regard to his or her own disability.

In social science circles the social theory/model of disability has taken the predominant role over the medical model. The four studies critique social theory in varying degrees and for differing reasons, all which have some impact on my study. Deborah Marks (1997) argues that the medical model is insufficient because it places deficiency within the individual because of the diagnosis instead on society or culture. Expanding the idea of disability as culturally and environmentally influenced would Marks says, improve life with a disability by encouraging cultural ideas about disability to change and expanding social policies and instructional practices with regard to disability.

While Marks (1997) stands by the social model for its implications with regard to politics and policy, Swain and French (2000) make adjustments to the social model and reframe it as the "affirmative model". The affirmative model directly challenges

presumptions of personal tragedy and the determination of identity through the value-laden presumptions of non-disabled people. It signifies the rejection of presumptions of tragedy, alongside rejections of presumptions of dependency and abnormality. Whereas the social model is generated by disabled people's experiences within a disabling society, the affirmative model is borne of disabled people's experiences as valid individuals, as determining their own lifestyles, culture and identity. The social model sites 'the problem' within society: the affirmative model directly challenges the notion that 'the problem' lies within the individual or impairment. (p. 578).

The important concept in Swain and French's (2000) affirmative model is that it embraces the idea of viewing disability from a "non-deficit" perspective that Mertens (2009) maintains is vital when working with both disability and the transformative methodology. It does however tend to gloss over the inconsistencies and challenges of living with a disability. The article itself takes on the "supercrip" tone that Vaughn Switzer (2003) describes, without seeing any of the raw materials for the study it is difficult to ascertain whether this was an intentional guiding by the authors or whether this was how the study participants felt about their own experience.

A third critique comes from an early work by Paul Abberly (1987). Abberly was an early voice for the inclusion of the concept of oppression when discussing any social model or theory of disability.

Apply[ing] the notion of oppression to the complex of impairment, disability and handicap involves the development of a theory which connects together the common features of economic, social and psychological disadvantage with an

understanding of the material basis of these disadvantages and the ideologies

which propagate and reproduce them (p. 17).

What Abberly (1987) is emphasizing is the need for theory that recognizes the

myriad of issues facing people with a disability and acknowledges that systematic

oppression plays a role in those struggles. Since Watermeyer and Görgens, are still

discussing the need to talk about the role of oppression in living with a disability as

recently as 2014, then any research done must acknowledge both the complexity of

disability and the frequency of "deficit" style language used to discuss it. Abberly was

looking for a systems theory style approach.

Hogan and Llwellyn (2000) provided just that. They used a general systems

approach to study children with physical disabilities. Using systems theory allowed them

to examine "the synergistic influence of the characteristics of the person, and of the

environment that produces the behavior" (p. 160), and recognize that through using the

systems approach, "There is a de-emphasis upon the importance of objective testing and

an emphasis upon real-life contextual research" (p. 160). The emphasis on real-life

contextual research and de-emphasis on objective testing is a hallmark of the

transformative method of research (Mertens, 2009). Hogan and Llwellyn's endorsement

of a systems style approach to disability is an affirmation that using complexity theory is

a more sound chose than any of the other theories commonly associated.

The two studies that have direct impact on the research are meta-analysis studies

by Antonak and Livneh (2000) and Nowicki and Sandieson (2002). Both studies

assessed attitudes toward people with disabilities. Antonak and Livneh investigated the

attitudes of professionals and adults most likely to come in contact with people with

disabilities. Nowicki and Sandieson used the attitudes of school-aged children toward

people with disabilities. Both studies acknowledged that attitudes toward people with

disabilities had profound impact on services and policies dealing with disability. The

studies suggested using the semantic differential scale and an adjective list as means of

measuring attitude. Each of those would be useful to incorporate into the research, either

has parts of a survey or for comparisons purposes when analyzing content. Another

study that could help guide the research is the content analysis done by Slebodia

(2013). This analysis focused on the language used in "the field of disability in the two

countries", (p.1). Slebodia used content from the Disability History Museum in the

United State and a Polish website. The language was separated into categories of

"Stigma" and "Other", with "otherness" being words that reflected ideas of love or

respect. Slebodia's analyzed material is far narrower in scope but is still another way of

looking at deficit versus non-deficit language and so provides a reference point for this

study.

     In the final relevant study with regard to perception, Li and Moore found that the

greater the internal acceptance of an individual's disability, the more likely that person

would feel as if they were a valued member of society. This study contrasts with all the

others because it looks at self -acceptance, or the acceptance of one's disability as the key

to better integration into society, whereas the previously mentioned authors focused on

the perceptions of others as being the key focus of the studies. Li and Moore (1998)

state, "Self-acceptance allows a person with a disability to identify more strongly with the

larger constituency of persons with disabilities. This process of self-acceptance may be

necessary for empowerment and full integration into society" (p. 22). Authors such as

Marks (1997) would argue quite strongly that such thinking disregards policy and cultural impacts on the disability experience. The line of thought that the individual with the disability is responsible for their sense of belonging is difficult to find in today's literature, but perhaps it is an idea to be on the watch for as materials written by those with disabilities are included in the analysis. There are additional studies that provide both relevance and background to studying the relationship between language and disability.

A 2018 study directly tied attitudes about autism to the dehumanization of autistic people (the term chosen by people diagnosed). What makes this study unique and important is that it examined the attitudes toward autistic adults from the perspective of autistic adults and not as is commonly done from the perspective of parents with autistic children. The study directly challenged many preconceived notions about the autistic community that if anything has been further perpetuated by research. The first myth about autism is that people with autism cannot understand nor display empathy (Cage, Di Monaco, & Newell, 2018). The reality is that autistic people can understand and display empathy they just may do it in a way that is not considered socially appropriate or neurotypical. This misconception causes autistic people to feel the need to hide their diagnosis because "coming out" as autistic would make them feel as though they would not be accepted by people. Other misconceptions about autistic traits such as stimming are often seen by the general public as making the non-autistic dominant population uncomfortable and more likely to "other" people with autism in their treatment of them.

There are two additional pieces that help expand perception as a concept in different ways. The first is Brune and Wilson (2013) discussing the idea of "Athlete first", the effort in masculinizing the perception of disability through sport. The second piece is Titchkosky (2011) discussing the perception of disability by means of access. Brune and Wilson (2013) also discuss the language used to perpetuate the perceptions of disability that ableism tries to achieve, and, in that way, they can also speak to the challenges of language surrounding disability.

Passing as an "elite disAbled athlete" was how injured men returning from war were encouraged to reintegrate into society after World War II with the precursors to what would later become the Paralympics. The goal of parasport was to give those who acquired disabilities an opportunity to mask their disablement through participation in "normal" activities, and what was more normal for men than to participate in sport. It also makes able-bodied people comfortable because it allows for putting storylines on disability that makes it palatable because the athletes are "overcoming" or "triumphing" over their impairment. If an athlete can "overcome" their impairment, then they can be seen as at least closer to "normal" than if they cannot.

> It seems that some disabled people can - in the rhetoric of dominant culture 'transcend' impairment...yet people living with impairment know that their lives are neither this simple nor this tidy. Impairment is always present, even in its absence, and the material effects of living life with impairment remain pervasive and persistent despite often well-intentioned efforts at 'inclusion'. In the end, erasing disability through the overcoming narrative does little to alter the realities of living with impairment and in most cases serves the power of

dominant culture by negating meaningful collective critique of structural

inequities and second-class citizenship (Brune & Wilson, 2013, p. 116).

Brune and Wilson take a direct approach at calling out the fact that so much of the

perception of disability, including the words and narratives used talk about, are used to

pose disability in a way that makes it more comfortable and palatable for the non-

disabled dominate culture. Titchkosky (2011) takes a different approach. She says that

perception of disability is built directly into whether a space is considered accessible. In

her book *The Question of Access: Disability, Space, and Meaning,* Titchkoksy relays five

real life situations about the university restrooms and universal access signs that illustrate

that disability is perceived through reasonable exclusion not real intent or efforts at

inclusion.

The first story is that of faculty and staff at a university who maintain they fought

hard for twenty years for ramp access at the front door of a main building on

campus. The signs for universal access were posted before most structures on campus

were actually accessible. When it was pointed out to them that a universal access sign

was posted outside an inaccessible bathroom their response was 'How were we to know

any better?' The second story is about a group of human rights lawyers who rented space

form meetings at the university. Some of the lawyers in the group who used wheelchairs

began to ask for the university to supply a wheelchair accessible restroom. When the

university did not provide the requested accommodation, the group took their meetings

elsewhere. In the group's absence universal access signs were posted outside of still

inaccessible restrooms.

The third story is of a conversation that took place between those who were responsible for allocating funds to make the buildings wheelchair accessible. During the conversation they were discussing that students in wheelchairs never actually came to campus so why should the university bother with the expense of making facilities accessible. Once again universal access signs had already been placed. The signs they considered better than nothing. The conversation took on a tone of agitation when it was pointed out that students in wheelchairs were getting stuck in restrooms marked as accessible to which someone "pointedly reasons, 'if they can't use the washrooms what are they doing here anyway?' (Titchkosky, 2011, p. 75). In the fourth story there is discussion about using funding to build an accessible restroom.

> Administrators, officially responsible for making structural decisions and
> allocating funds, say that they are working on it. You can't do everything in a day.
> In fact, maybe we need to just slow down. Thirty years ago, in good faith, the
> signs were put up and it is possible, that within the decade, we might be moving
> to a new building. 'Remember', they say, 'we did secure the special fund to build
> an accessible show case classroom. Maybe some of that fund could be used to
> build the washroom?' (p. 75).

The final story is her own. When she as a wheelchair user pointed out that she was being asked to work in a building that had no accessible bathroom. She said the people she worked with were "perplexed by the inaccessibility, and those in authority did not seem to take it as a crisis that [I was] working in a building that doesn't have a washroom" (p. 75). When she asked if the misleading universal access signs could be removed, she was assured the would be. The signs are still up, the bathroom still not

accessible. This was when she first began working at a university that had asked her to come build a Disability Studies program. "What place could disability studies have in a location that sported so little space for disabled people? (p. 7). Access Titchkoksy says is the perceptual consciousness that allows or excludes disabled people. "it needs to be understood - as a complex form of perception that organizes socio-political relations between people in space" (p. 4). Titchkosksy's work in disability studies is considered a cornerstone of that field. So much so that her book *Reading and Writing Disability Differently: The Textured Life of Embodiment* (2007) served as some of the founding literature on the discussion of language and disability. Pothier and Devlin's (2006) work is as well as Titchkosky's work itself is an appropriate starting point to discuss language and disability.

Language and Disability

In setting up the foundations of critical disability theory Pothier and Devlin (2006) put "Language, Definition and Voice" as one of the main themes of the theory. Language attached to disability is so important they recognize that is a particular sticking and sometimes a stopping point in discussing disability. They point out that even dictionary definitions of disability are from Merten's (2009) deficit perspective and even the phrase disability as defined by Oxford as "want of ability". In that sense many have seen the use of the words disability or disabled as pejorative, but like the word "queer" it is reemerging among the disability community as an identity descriptor and it used with pride in many cases. The word disability itself however they point out is still used as a descriptor in the general population as someone who is less than what societies consider a normal human being. They note that women and racial minorities have been

subject to being less than human in both U.S. and Canadian constitutions but hold that disability is different.

> Part of the difference in language is that while the words "race" and "gender" do not themselves designate a specific subset of the population (and in that sense they are facially neutral), "disability" does explicitly engage in targeting (and in that sense is ideologically loaded) (Pothier & Devlin, 2006, p. 4).

> They also recognize that person first language is both political and a way to

separate disability from person hood making disability still "second order nature" we do not use the phrases "persons with a gender" or "persons with a race" (p. 4), thereby making able-bodied people more comfortable with impairment. They also note that the social, legal, and medical definitions of disability can vary widely. Which is why Titchkosky's (2007) sociological is useful in continuing to further understand that disability as concept and language is not a simple concept to examine.

Titchkosky discusses in both of her books (2007, 2011) her own experiences with disability and trying to cope with the language and perceptions imposed on her by others. She argues strongly that the fundamentally understanding or definition of disability as a negative condition and from the framework of not is inherently responsible for the disenfranchisement of disabled people in both their ability to simple exist and be seen as person regardless of what their capacity for production as citizen is

> Disability is being constituted as an unnamed condition of difficulty that reduces the activity and is to be measured against some idea of normal activity at home, work. or play. This is a conception of disability that evades and even obliterates any kind of social identity or collective politics. One can no longer, perhaps

never should 'be' a disabled person since it is assumed to be more positive to be a

person with difficulty, or difficulties whose activity in the realms of daily life is

limited. What is defined as disability is a negative condition of lack and limit,

and, as such there is no point in being such a person. Instead the best that can be

hoped for is that a person who happens to be conditioned by bodily difficulties but

[is] limited [by those difficulties] as little as possible (Titchkosky, 2007, p. 75).

She says that because disability is only ever seen as negative that people miss the

possibility to use to the framework that has been set up around disability as an

opportunity to "examine neoliberal culture" (p. 1). She also discusses the phenomenon of

what she calls the "able-body" disabled, these are the narratives told in the media about

"overcoming" disability to be productive citizens, like Brune and Wilson (2013) these are

the narrative that the public and the government prefer because they sanitize disablement

and promote the productive citizen agenda which neoliberalism has come to

promote. Her perspective of how disability is written and read about is powerful and

purposeful, she like other writers and researchers still acknowledges that disability is

somehow that elusive concept that is more complex that just a positive or a negative.

One of the most challenging aspects of discussing disability, from either a policy

perspective or an attitude perspective, is defining what "disability" means. Mitra (2006)

suggests the capability model as an alternative to other models of disability because it

breaks disability down into three definable categories. It is Mitra's claim that reaching a

consensus on the definition of disability is problematic and using the capability model

would allow for across the board agreement on defining disability. The capability

approach would determine and define disability according to the following factors: 1) the

potential level of impairment an individual sustains because of disability in conjunction with additional demographic factors such as race and gender, 2) the environmental factors that may limit the individual's ability to achieve independence, and 3) the functional capacity of the physical disability – that is what the person is physically or mentally capable of accomplishing. This viewpoint Mitra says is vital to looking at the economic impact of disability on both the lives of people with disabilities and the overall economic impact of disability on community.

Mitra's need to define disability points to a larger discrepancy surrounding language and disability. The discrepancy in the way different groups view and use the language that surrounds disability is not new. In 1994 Irving Zola said that the word "impairment" had taken on a medical designation, while "disability" was more of a social one, but even in the 1980s they were lacking consensus about language surrounding disability, and it still seems to remain elusive.

As previous social movements acknowledge, what one is called is more than a matter of semantics. Although no universally accepted terms have yet been established, there has been a shift away from pejorative associations (cripple, handicapped, lame, deaf and dumb) to more "people-first" designations. Governmental agencies and private organizations have quickly followed suit (Zola, 1994, p. 60).

Multiple studies affirm the various attitudes and uses of language, but three used the Attitudes Toward Disabled Persons (ATDP) scale for their research with varying results as to way disability language was not consistent. Harold Yuker, J.R. Block and Janet Young created the ATDP in 1970; it has been the most widely and frequently used measurement tool to gauge people's attitudes about individuals with disabilities.

In a study of three hundred Wisconsin government employees that were all asked to take the ATDP, the study's author, Ruth Lynch (1994), reported that the majority of participants agreed that person-first language was the most appropriate way to refer to people with disabilities as opposed to disability-first language as a more adequate descriptor. However, two-thirds of the participants felt there was really no difference in person-first language versus disability-first descriptors. When asked if the one type of language or the other would influence job applications, participants said either language was acceptable, and one was not more influential than the other. Lynch found no differences in viewpoints with regard to language preference when she categorized participants based on education levels or awareness of the A.D.A.

Another study that used the ATDP was conducted at an undisclosed university in the Midwestern United States. In this study, three hundred fifty-one psychology students, who were minors, majors, or graduate students of the university's psychology program, were asked to gauge their thoughts on disability. 3) found similar results to Lynch (1994). While results were mixed they said that few students were likely to use person-first language and it appeared that the use of language and attitudes toward disability had parallel relationships. In addition to the ATDP scale all three of these studies referenced a 1987 Patterson and Witten study that postulated humanizing language eventually humanized behavior toward marginalized groups. In their study Patterson and Witten (1987) linked the change in language usage toward Black Americans in during the 1960's civil rights movement to changes in both attitude and treatment of the given population.

The civil rights movement was accompanied by a change in terminology from "Negro" to "black." …Attitudes toward a group can be expected to change when the

humanizing implications of a particular word change gradually become reflected in a growing awareness of the potential of the group (Patterson & Witten, 1987, p. 247).

Gouvier and Coon's (2002), acknowledging that language was impactful on perception, conducted a study that says language is the key to removing fear and misunderstanding around disability. They recognized that common phrases and words used to describe disability may not bother those without disabilities, but can often "find [such] language patterns ingratiating and irritating, even when no slight is intended by the speaker" (p. 55), further they call for the empowerment of people with disabilities to "take the lead as coaches teaching people without disabilities" (p.55) with regard to any misconceptions that people without disabilities may have.

Grames and Leverantz (2010) wanted to study the difference in attitudes toward people with disabilities from the perspective of two different groups. They presented the ATDP to Chinese international college students and American college students and asked them to rank their attitudes about people with physical, cognitive, and mental disabilities. Grames and Leverantz expected to find U.S. students to have more favorable attitudes toward people with disabilities of all types, but instead found that Chinese international students' scores on the ATDP indicated they had more favorable attitudes and reactions to people with all kinds of disabilities whereas the American students responses indicated only slightly more tolerant for people with physical disabilities than cognitive or mental disabilities.

The value in the Joines, Kapkin, and Valenziano (2014) article is two-fold in that it addresses two issues important to the ensuing research. The first is point contends that all research surrounding disability should be done so using person-first language and that

to not use person-language is disparaging to research participants and goes against best practices in research design. Their second point is an unspoken advocacy for transformative methods research with will be dealt with later in paper.

A most unusual and salient piece of research thus far comes from support professionals for people with disabilities. Peers, Spencer-Cavaliere, and Eales (2014) argue against person-first language for non-medical reasons. Many medical professionals and those in medical professional support fields use language that focuses on the diagnosis not the person, but in a piece written to the editorial board of their professional publication Peers, Spencer-Cavaliere, and Eales claim that the publication requiring practitioners to use person-first language is out of line.

[Although] well-intentioned it betrays a very particular cultural and disciplinary approach to disability: one that is inappropriate given the international and multidisciplinary mandate of the journal. Further, we contend that *APAQ's* current language policy may serve to delimit the range of high-quality articles submitted and to encourage both theoretical inconsistency and the erasure of the ways in which research participants self-identify (Peers, Spencer-Cavaliere, & Eales, 2014, p. 265).

What is interesting about their argument is that it falls more in line with disability activists' assertions that person-first language is not always helpful or welcome (Landau, 2014). All of the authors who have written on disability and language agree that the language used matters, but there is little agreement about the mores surrounding the language, which is why an overview of the types of language currently used to discuss disability is important and timely. Now more so than now that many people with disabilities and advocacy organizations feel that the needs of those with disabilities will

be pushed further to the margins with the changes occurring on governmental levels (National ADAPT, 2017).

There does however seem to be growing consensus among disability advocates and researchers that the phrase "special needs" does more harm for people with disabilities than it does good. In a video for World Down Syndrome Awareness day 2017, actress Laura Potter, who has Down Syndrome, walk the audience through what it would look like if people with disabilities really had "special needs". Special needs she narrates would be "special" if they needed things like massages performed by cats, or a diet of dinosaur eggs. "Jobs, education, families, and kindness are not special needs. They are human needs" she says (Jusino, 2017, para. 4). More and more there is public discussion that the phrase "special needs" is not useful in advocating for the needs of the disability community. In 2016 a research article advocated for discontinuing to use the phrase. Gernsbacher, Raimond, Balinghasay, and Boston (2016) maintain the euphemism is ineffective and negatively impacts the perceptions of both adults and children with disabilities when they did a side by side comparison of free association words for both "disability" and "special needs". The study cites the Research and Training Center on Independent Living as saying "terms such as *special*, *handi-capable*, *differently abled* and *challenged* reinforce the idea that people cannot deal honestly with their disabilities" (p. 3). The word association portion of the study found that word associations with the phrase "special needs" were forty-nine percent negative, thirty-three percent neutral, and eighteen percent positive. Word associations with the term "disability" were forty-one percent negative, thirty-seven percent neutral and twenty-two percent positive. Overall the research said that the phrase "special needs"

impacts people with disabilities in three ways. The first is that people associate the

phrase with special rights, different and distinct that what other people have. This the

researchers point out is patently false and this misconception leads to discrimination

against people with disabilities. The second area of impact is that the phrase connotes

separation. Because the phrase "special" appears in front of Olympics and education

there comes with that designation certain levels of isolation that separate people in those

activities from the general population. This separation is particularly harmful both in

perception and purpose for those with intellectual disabilities. The final area the research

condemns "special needs" is that the phrase is generic and lacks specificity in naming the

needs of individuals and the disabled community. "Special needs" could mean a child

with disabilities is less likely to be adopted because prospective parents may not

understand the specific care the child needs, more over the research notes that the same

phrase has been applied to interracial adoptions. The phrase could be addressing the

assisted living emergency preparedness to populations over the age of

fifty. Gernsbacher et al., (2016) add their collective voices to that of others calling to end

the use of the phrase. They however go one step further by calling special needs

a dysphemism, and they call out the fact much of the disability language has become that

way for the general public.

> It is unsurprising that "special needs" has become a dysphemism. Other disability
>
> terms have become not only dysphemisms but also dysphemistic metaphors
>
> (Pfaff, Gibbs, & Johnson, 1997). For example, among the definitions the
>
> MacMillan Dictionary (http://www.macmillandictionary.- com/us) provides for
>
> the term deaf is the denotation "not willing to listen to something" (e.g., deaf to

reason); for blind, one denotation is "unable to realize or admit the truth about something"; for crippled, one denotation is "damage[d] severely" or "prevent[ed] from working properly"; and for lame, "done without much effort in a way that seems as though you are not trying very hard." Although deaf, blind, crippled, and lame originated as disability terms, they are now commonly used as dysphemistic metaphors (Gernsbacher, et al., 2016, p. 10).

Indeed, Gernsbacher et. al. (2016) legitimize through research what advocates and people with disabilities have been saying for decades. The language used to discuss disability is intricately tied to how people with disabilities are treated. What is more they acknowledge that it is people with disabilities that ought to be leading the conversations on language.

In addition to the previously mentioned studies, in order to find literature on disabilities that was not academic in nature, the review of literature included materials from blogs and online sources whose main audience is people with a pre-existing interest in issues surrounding disabilities. Even when the topic of disability is covered in public venues such as media, instead of academic or scientific literature, the stories are often about the person with a disability being the victim of another's cruelty or as an inspiration for overcoming some adversity brought on by the person's disability. Many sources discussing disability are open forums for people to ask accommodation questions or come together for supporting dealing with the multiplicity of issues that arise from having a disability.

Online sources like "The Mighty", a website for the disability community to discuss a wide variety of issues, and "Disability Scoop", an online newsletter that labels

itself "the premier source for developmental disability news, with daily coverage",

certainly would be questionable sources for academic study or research, but that is what

is publicly available outside of the occasional stories that appear in mainstream news or

academic sources. There are groups with significant online presence like CP.org or

Disability.gov that publish articles on their websites and have Facebook and Twitter

accounts. These articles vary in content. They can be anything from championing the

need for disabled employees in the workplace to celebrating the success of an individual

with a disability, who has achieved something considered outside the expectations for

people with disabilities. It is these sources that will provide the bulk of the material for

analysis because they are easily accessible to the public.

Cautions

The literature indicates researching disabilities can be a challenge on many levels,

but Moore, Beazley, and Maelzer, (1998) and Rosenblum and Travis, (2012) cue in on a

concept that needs to guide the research. The research must not contribute to the further

marginalization of people with disabilities. Design, execution and collection must be

monitored to avoid inadvertent or purposeful discrimination against people with

disabilities. Rosenblum and Travis give example of a survey given in 1986. The

questions where all formed in such a way as to find fault on the part of the person with a

disability "Can you tell me what's wrong with you...What about your disability makes it

difficult for you to travel" (p. 168). The language used in research questions can greatly

affect the answers given, so it is important that questions are carefully vetted for biased

language. It is also important to examine the words that keep reoccurring during the

qualitative portions of the research because that can provide a great deal of understanding about perception.

Language and Terms

Use of language and terms is not just to be considered while conducting research but throughout the whole writing process and most sources used thus far have taken at least a page to discuss the importance of language when discussing disability. Nielsen (2012) points out that as much as scholars might try to be careful with the language used, current language trends like fashion are bound by their place in history and always subject to change. Vaughn Switzer (2003) points out that clarity of language or lack thereof can drastically affect policy interpretation. Scholars like Zola (1994) and Knight (2013) take the time to meticulously define each term used, carefully differentiating terms like "impairment" and "disability" one being a medical definition, the other being a social definition.   As a reader such an approach can feel cumbersome and on the verge of getting lost in categorical jargon. The literature is multidisciplinary so there is little to no consensus about appropriate word choice or terms to use when discusses disabilities issues; It is for this reason that the language and terms used throughout this process will be primarily contextual and specific terms and definitions given where they are the most vital.

Chapter 3: Research Design

What is the Transformative Paradigm?

Because the language we use is so vital, it in and of itself is worth studying. How and why we study it is also important. Using transformative research and evaluation helps in the study of the language that surrounds disability. Mertens (2009) says she changed the name of the emancipatory research paradigm to the transformative research paradigm. The emancipatory paradigm was one of four major paradigms used in psychological and educational research that found their roots in both Kuhn (1996) and Guba and Lincoln (2005). As an instructor and researcher at Gallaudet University for the Deaf, she liked the phrase emancipatory because she felt that the people involved in that type of research ought to recognize their capacity as agents for change. Mertens felt the role of change agent was true for both the researchers and the research participants.

The transformative methodology goes steps beyond the emancipatory paradigm because it is a "means to bring [marginalized] voices into the research" (Mertens, 2009, p. 3). By sharing in the research as "equal partners" with the researcher, those populations that have been continually marginalized have an opportunity to affect the growth of human rights. Creswell and Plano Clark (2011) add, "the purpose of this design is to conduct research that is change oriented and seeks to advance social justice causes by identifying power imbalances and empowering individuals and/or communities" (p. 96). Creswell (2015) goes as far as renaming the method the "social justice design" (p. 45).

Creswell and Plano Clark (2011) explain that this is a method deeply guided by philosophical and theoretical conventions. The design itself dictates that both quantitative

and qualitative research occur. The theoretical perspectives are woven throughout both sets of data and used to recommend changes or calls to actions.

Why is it important and how does transformative paradigm enhance the research?

Transformative research is appropriate as a paradigm this specific research for multiple reasons. First, because such research invites and includes marginalized perspectives in the research it helps to protect against what Moore, Beazley, and Maelzer (1998) consider the manipulation of the marginalized population and the research for the purposes of those outside the research. Recognizing and stating from the outset of the research that its purpose is to enhance the standing of a marginalized group or inform the general public of the status and strivings of a marginalize group can help dispel concerns of bias within the research. Both Mertens (2009) and Creswell and Plano Clark (2011) acknowledge that some research must be done to further the cause of marginalized groups, and as the leading researchers in transformative research and evaluation, all of them contend that this methodology is designed to be a form of advocacy as much as it is informative research. Mertens gives multiple self-checks and balances ways within the research design itself to stave off bias.

Another reason transformative research and evaluation is suitable for this study is the role of self-determination in both the research method itself and conflict studies as a practice. Bush and Folger (2005), Cloke (2001), and Winslade and Monk (2000) discuss self-determination as a cornerstone to conflict solving processes and experiences, as self-determination is a concept that Mertens (2009) says is vital to transformative evaluation because it includes the research participants in the process and outcomes of the research.

Since both conflict studies and transformative evaluation place a premium on autonomy, the research method is a good fit for dissecting language as it relates to the policies and perceptions of people with disabilities. The calls for academics and support professions to honor and include individuals with disabilities and disability as identity in research have been around for twenty-five years.   One of the earlier calls about making participatory/emancipatory research systemic came Zola (1994). It was Zola's contention that no research on disability policy be funded unless the research was designed to include people with disabilities as direct participants not just subjects. He called the concept of participatory/emancipatory research an "essential element" and demanded that more researchers and policy makers use the inclusive process.

Beyond Zola's call for inclusive research to be mandatory to receive funding, oft cited disability researcher Mike Oliver (1997) said that participatory/emancipatory research as it was in 1990s was not enough and needed to change. In what is considered a foundational publication among disability researchers *Doing Disability Research* edited by Colin Barnes and Geoff Mercer, Oliver makes the case that participatory/emancipatory research is meant to be a vehicle of change and it needed to do a better job than it had been doing. This was primarily because the research worked within existing power structures only serving to strengthen them instead of changing them to better serve individuals with disabilities. Oliver felt strongly that the participatory/emancipatory research paradigm needed to confront existing power structures and push them to implement needed change for the disability community.

In the same book as Oliver (1997) Linda Ward (1997) argued that it

was "[B]eyond a basic right to be consulted in research which affects your

life…[E]xpectations about research involving disabled people, states clearly that they should be involved in all stages of the research process…as originators of the research idea; as advisers or consultants to a research project; as research workers or interviewers; and as disseminators of research findings (Ward, 1997, pp. 36-37).

Vernon (1997) supports Ward's (1997) claim several chapters later in the same book. From a follow-up interview Vernon shared one participant's thoughts on the research. In the interview the participant shared that it was not until she contributed to the study that she realized how difficult life as a black woman with disability had been. She said, "you usually just push it to the back of your mind and get on with your life and try not to think about it" (Vernon, 2017, p. 170). Vernon goes on to explain that including people with disabilities in all stages on the research can help provide the kind of realization her interviewee had. She is adamant that inclusive research can be used to share experiences and build both individual and community identity.

Three years after the publication of Colin and Mercer's (1997) work, Kitchin (2000) was reporting that people with disabilities are being used and then summarily ignored by researchers using emancipatory design. According to those he interviewed: despite the willingness for those with disabilities to participate in the research, they felt nothing changing for them even though the researches have made them aware that is the goal of the research. In expressing his frustrations with the emancipatory model, Kitchin says he believes in the value of the research design and its purposes, but says it still needs to occur more often and o wider use, so that it can be refined in a way that allows it to

fulfill its purpose. Kitchin is not the only scholar calling for a refined practice on inclusive research.

In 2003, Colin Barnes made an impassioned defense of emancipatory research saying that in the decade since he and Mercer published their book that the research was making great strides and that "when directly linked to disabled people's ongoing struggle for change, doing emancipatory disability research can have a meaningful impact on their empowerment and the policies that effect their lives" (Barnes, 2003, p. 14), while at the same time acknowledging that the paradigm and its researchers are struggle to be accountable for the promises of change the research is making. Barton (2006) adds to Barnes' argument by saying the researchers using this paradigm need to "thoroughly understand and practice the art of 'listening' to the voices of disabled people. They are not to be received uncritically and this does entail engaging with those difficult, unexpected or previously silenced/ignored perspectives" (p. 325).

The case is still being made for both the importance of the transformative paradigm and its refinement. As recently as 2012 and 2014 researchers using the paradigm, which still seems to be fluctuating between the terms participatory, emancipatory, social justice and transformative, were still calling for a reworking and refinement of the research process. As mention previously Joines, Kapkin, and Valenziano (2014) called out their profession for using person-first language almost to determent of those with disabilities. They also take their colleagues to task for not using research design procedures that are more inclusive of their people with disabilities. Nind and Vinha (2012) went further than many researchers in specifically naming the aspects of the transformative paradigm that need to change.

Nind and Vinha (2012) were inspired by Freire's (2009) concepts of liberating dialogue. They wanted to openly acknowledge the dual role as participant-researcher without having to bracket the contributions from either role. Additionally, the concepts they felt were the most important to transformative research were listening, reflecting and transforming, they "wanted people traditionally with and without power to be 'naming the world' together and not 'on behalf of another' (Freire, 1970; 69–70). The dialogue needed to reach across people with different kinds of experience and expertise" (p. 103). As they carried out their focus groups with regard to refining the transformative design, they determined that transformative design is still too new of a paradigm to "pin… down too tightly the research approach that we call inclusive research" (p. 108). The concern they found among their focus groups was that because transformative design is not widely practiced, by putting too many parameters on it, the paradigm runs the risk of becoming too exclusive and not achieving he purposes for which it was intended.

The agreement among all these scholars is that the transformative paradigm is vital to researching disability. They agree that theoretical approaches are a key aspect of the paradigm. Those are about the only principles in the transformative paradigm that are agreed upon. For any other research or field that would be problematic, but for conflict resolution fields and for this research the transformative paradigm allows for exploration and discovery while leaving room for creativity and innovation in dealing with the issues that arise from policies and perceptions surrounding disability. By using this research paradigm and content analysis to investigate what is happening with disability language and policy from a far it is conceivable that this study could provide recommendations for

refining not only language and policy with regard to disability, but also help the refinement of transformative design and evaluation.

Theoretical Guides for Research

Transformative research and evaluation are grounded in theoretical assumptions and requires that the quantitative portion of the research be based in the applicable theories. Therefore, it is important to acknowledge with the topic of disability language as it relates to public policy and perception, that it is first and foremost a complex issue so there are multiple theories that will help guide the research. Some of those theories may guide the research more than others.

One of the challenges that Mertens (2009) and Creswell and Plano Clark (2011) cite with transformative research and evaluation is that more often than not, minority or unrepresented groups in research tend to be examined in terms of what they lack compared to other more visible or researched groups. Researches look at what groups do not have instead of what they do have, because of this Mertens strongly recommends not using a non-deficit approach in transformative research.

Avoiding the deficit approach with this particular research is difficult from the outset because of what is missing - any widely agreed upon disability theory. The most common models of theories applied to disability are the medical and social models and identity politics, which many scholars and activists find inadequate (Auterman, 2011; Brayton, 2015; Charlton, 1998; Gerschick, 2000; Kim, 2011; Knight, 2013; Siebers, 2008; Nielsen, 2012; Vaughn Switzer, 2003; Withers, 2012). Even when discussing theories that fit well with transformative research Mertens (2009) and Creswell and Plano Clark (2011) use the term "disability lens", whereas with other minority groups they use

the theories like feminism and queer theory. It is of the utmost importance to the research to point out that while other groups have an agreed upon theory, disability research and scholars have yet to agree, and that is why for the purpose of this research the primary theories in which the research will be grounded are complexity theory, muted-group theory, critical disability theory, and social justice theory.

Complexity Theory

The particular framing of complexity theory that is the most useful for this research is Morgan's (1998) concept of cultural complexity. His viewpoints are salient to the research because it allows for acknowledgement of the complexity of disability and the language and policies that surround it. The social model of disability does not address the medical issues that are part of living with a disability. The medical model focuses on disability as a problem that needs a cure. Political identity theories only cover a portion of the issues faced by people with disabilities. Cultural complexity viewpoints mean the research can include all those issues because they are inseparable. The tools that the cultural complexity theory provide fit appropriately with the five categories in the World Health Organization's (WHO) (2010) matrix of issues that should be addressed for people with disabilities, those categories are health, education, livelihood, social, and empowerment [political]. Such categories provide a useable representation of cultural complexity when it comes to disability and language. The WHO categories are particularly salient because they recognize that policy and perception of people with disabilities are intertwined and difficult to address separately, especially in the language used to describe the disability, the person, and the policy.

Muted Group Theory

Kamarae's (1981) research and subsequent theory on the use of language as it pertains to women and men is relevant to the research for several reasons. First, her research provides a guide in evaluating language usage in regard to minority groups. Because she looked at language as it described women, much like my research will look at how language is used to describe living with a disability, her research will provide a measurable test as to whether or not language used in relation to disability fits the muted-group theory. The theory being that groups who do design or control the dominant discourse and language about themselves then become subject to isolation and oppression. Since muted-group theory maintains that language usage can lead to isolation and oppression and Merten's (2009) maintains the importance of doing research that does not come from a deficit perspective another theory that can help guide the research is social justice theory.

Critical Disability Theory

Pothier and Devlin (2006) take on disability theory from primarily legal angle. Critical disability theory is an outgrowth of critical legal theory. The reason this theory is distinctive to examinations done under the transformative research paradigm is that it provides foundational understanding for much of the disability experience. That experience Pothier and Devlin argue is based in politics that surround disability, fundamentally the fact that the politics of disability are a power issue more than any other issue. They concur that the medical and social models are incapable of addressing the underlying ability for disabled people to enjoy full citizenship because not only are disabled people politically disadvantaged because they are disabled, but able-bodied

people are given privilege over disabled citizens. Critical disability theory is needed to

address and rectify this imbalance that they argue has permeated both the politics and

legalities of disability.

> Our central arguments are that disability is not fundamentally a question of
>
> medicine or health, nor is it just an issue of sensitivity and compassion; rather, it
>
> is a question of politics and power(lessness), power over, and power to. Its goal is
>
> not theory for the joy of theorization, or even improved understanding and
>
> explanation; it is theorization in the pursuit of empowerment and substantive, not
>
> just formal, equality. The problem is not just the disadvantaging of persons with
>
> disabilities but the privileging of those who are perceived to be non-
>
> disabled. (Pothier & Devlin, 2006, p. 2).
>
> The claim that disability is not just an individual impairment, but a systematically
>
> enforced pattern of exclusion moves the analysis forward in important ways.
>
> However, it also raises a number of other questions. For example, as Malhotra
>
> points out in Chapter 3, there may be significant differences between a social
>
> model, a social constructionist model, and an oppressed minority model, each of
>
> which might characterize the problem, and potential solutions, differently (Pothier
>
> & Devlin, 2006, p. 14).

Social Justice Theory:

The reason that social justice theory helps provide a framework for the research is

that it already holds as part of the theory many things the research is attempting to

examine and can therefore be used as a lens that provides a checks and balances

mechanism for the findings. Rawls (1999) maintains that social justice theory

acknowledges that social systems and structures create equity or inequity. Because of this finding it is extremely difficult to try to examine the perceptions that the language about disability creates without in fact looking at the policy that governs disability in America.

Social justice theory also ties in with Mayer's (2015) paradox idea about the challenges of balancing autonomy with community. Mayer contends individuals need both a sense of community and independence. Rawls (1999) says that social justice theory hinges on balancing the rights of the individual with the rights of a collective group and the rights of one group versus another. The language used to describe people living with disabilities is bound to have an effect on the perceptions of them and the rights people think they ought to have. As it stands now according to the ADA if the right of the individual with the disability to an accommodation is deemed "unreasonable" then the right of the individual is usually sacrificed to the right of the institution.

From both a conflict resolution standpoint and a pedagogical perspective social justice theory-based education can aid in the building of communities. Mayer's (2004) idea about the need for less neutrality on the part of conflict resolution practitioners also fits well with social justice theory as a key part of the research because if they were given the right training in the issues surrounding disability conflict resolution teachers and practitioners could help in conveying and implementing the research findings.

From a pedagogical standpoint social justice theory "aims to help participants develop awareness, knowledge, and processes to examine issues of justice/injustice in their personal lives, communities, institutions, and the broader society" (Adams, Bell, Goodman, and Joshi, 2016, p. 4). Their point is pertinent from both an in and out of

classroom perspective on educating people about the experiences of people living with disabilities. Social justice theory is perhaps one of the most useful viewpoints from which to make recommendations based on what is found in the research, especially since transformative the whole intent of transformative design is to make recommendations about changes that will benefit a marginalized group.

Methodology

Researchers are finding rich and significant materials in the process of content analysis on social media. Hamad, Savundranayagam, Holmes, Kinsella, and Johnson (2016), argue that textual analysis is both qualitative and quantitative in nature and offers "quantitative and qualitative methods offer a more flexible alternative" (para. 20). They continue:

> Those who are interested in ideology, political approaches, or theoretical frameworks (e.g., critical theory, advocacy, or participatory research) aimed explicitly at societal change can use a transformative design with CA. The CCA design is useful when the researcher has more than 1 question best addressed through the use of multiple methods, or when the aim is to gain the best from each method by combining them to address a particular question (para. 20).

Using content analysis on social media provided multiple benefits. First, it allows for the viewpoint of marginalized groups and individuals to be observed without running the risk of people changing their viewpoints to fit the research objective while protecting populations considered vulnerable by IRB research protocol. Second, content analysis through social media provides a wider range of data to work with than strictly relying news coverage to cover disability related topics. Third, in conjunction with providing a

wider array accessible of data, using social media allows for a larger selection of viewpoints to be analyzed. Social media content analysis included materials from disability focused nonprofit and government organizations, disability studies instructor groups, individuals and support groups for disabled people, with much of the content coming from Facebook groups likes the Disability Visibility Project, Representing Disability in an Ableist World: Essays on Mass Media, and Teaching Disability Studies. Forth, tools like Nvivo's Ncapture enable the direct pieces of data to be copied and imported for analysis with minimal disturbance to the raw material.

It is important to note that in order to access the content for analysis I was required to join or follow multiple public groups through my personal Facebook account. At no point during the time that I was collecting data did I interact with the group members or posts; I wanted to observe and analyze the content through screenshots of the material through Nvivo's screen capture process in accordance with the exploratory research design.

Fifth, social media has become a vital aspect of life for many of its users, "For many, particularly people from marginalized groups, social media is a lifeline – a bridge to a new community, a route to employment, a way to tackle isolation" (Ryan, 2018, para. 5). Lai and To (2015) contend that drawing directly from user generated social media content allows for researchers to get a better first-hand understanding of users beliefs, perceptions and values, thereby adding more valuable context to the research findings. Trevisan (2017) did extensive research of the use of Facebook on the mobilization of disabled British citizen to directly inform on both policy and invite the public to be aware of their efforts. "[Facebook] personal stories, most of which were

expressed in the first person, facilitated the emergence of disabled Internet users own un-mediated voices" (p. 145). Gathering "un-mediated content is vital to allowing the voice of the research subjects to come through especially in the case of participants with disabilities.

Based on the recommendations of Mertens (2007), Creswell and Plano Clark (2011), the best design for this research is convergent exploratory design. Creswell (2015) prefers this design's rigor and says that the exploratory nature of the design allows for some substitution of measures that may be dominant in typical research. The exploratory process fits well into the transformative paradigm. Creswell (2015) claims this as a three-phase study, however an example that will be used as a guide only used two phases that they derived from Creswell and Plano Clark (2011) using content analysis so it is closely related to this study.

Creamer and Ghoston (2012) analyzed engineering college mission statements looking for the inclusion of new engineering standards set in 2000 and whether the mission statements contained references to diversity being important to the engineering college's mission, in particular they were looking at gender diversity using keyword searches. Further exploratory content analysis research includes, Archibald, Radil, Zhang, and Hanson (2015); Louis Kajfez and Creamer (2014) used keyword searches as the basis for their content analysis and Snelson (2016) used keyword searches specifically related to social media content analysis. Lacy, Watson, Riffe, and Lovejoy, (2015) recommend "[i]n order to limit the role of individual subjectivity, researchers should draw upon the literature and previous studies to assemble multiple keywords… or keyword strings that offer more than face validity" (p. 6). While other research done by Bengtsson (2016);

Creswell, Klassen, Plano-Clark, and Clegg Smith (2010), suggest that multiple factors, including time and availability of research materials, ought to be considered when using mixed-methods studies.

In 1997 Erzberger and Prein were among the first researchers to use triangulation protocol in mixed-methods research. The purpose was to compare different research data sets to each other to determine related aspects of the parts of the research from both qualitative and quantitative perspectives.   Their research has been the basis for current research done in health and social science research. Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville (2014) (Farmer, Robinson, Elliot, & Eyles, 2006) and O'Cathain, Murphy, and Nicholl (2010) provide specific guidance for following triangulation protocol. Researchers are to list findings from each data set and analyze how the data sets compare to one another based on whether the data sets are in full agreement or partial agreement with regard to the themes found in the research data. Both research groups agree that silence and dissonance should be looked for while analyzing the data sets. Silence being that one set covers certain themes, while those seems are absent in other data sets, and dissonance being "meaning and prominence are different; provincial coverage and specific examples provided are different" (Farmer et al., 2006, p. 383). For the purposes of the study triangulation protocol was used in conjunction with Creswell's (2015) exploratory mixed-methods research.

Research Questions

The starting point of the study was to give some direction to the exploration. The basic questions that the study aimed to answer were: What topics in regard to disability were in the public sphere? Through what means were materials being made publicly

available? How was language being used in regard to disability? The research protocol set forth by Farmer et al. (2006) provided such specific steps that their protocol was used as an outline for handling and analyzing data.

Farmer et al. (2006) lay out six steps to the triangulation protocol. First step is to sort findings from like data sources into categories that help to address research questions. Second step is "convergence coding". Here commons themes are identified among data sources and the sources are labeled as to their level of agreement across themes. Convergence assessment is third step. The purpose of this step is to provide global assessment of themes and agreement levels across data sets. Completeness assessment is the fourth step where the "nature and scope of unique topic areas" for methods or data sources is compared. The fifth step in the protocol is to compare across researchers or compare with theories. In the case of this research, the comparisons will take place across the theories used as the research base. Providing feedback on research results to necessary stakeholders is the final step.

<p align="center">**Part I of Triangulation Protocol**</p>

Step 1: Sorting

The first step set forth in the protocol is to sort data. Sorting data according to (Farmer et al., 2006) means accounting for the sources from which the data came as well before codes are applied to the data. Data was sorted into two separate classification groups. The first classification was the sources from which the data came. Source classifications were defined as corporate, government, non-government organization/non-profit, and personal.

The second classification group was the type of data the material was considered. Supported by Haller's (2010); Ryan's (2018); Trevisan's (2017), evidence that social media's impact on disability discussion was a central aspect of the research, the decision was made to use convenience sampling from Facebook as the main social media outlet for gathering data. This decision was supported Lacy et al.'s (2015), assertion that convivence sampling is an appropriate way to get an idea of what is being discussed publicly about a specific phenomenon. The types of data sets were categorized as Facebook posts (FB Posts), website links available through Facebook (Website Pages), and news articles (News Articles) available through Facebook. All data was captured in its published form using Nvivo's Ncapture Chrome web-browser add-on. The data was saved in as portable document format and imported into Nvivo 12 for Mac.

Step 2: Coding

Triangulation protocol's second step according to Farmer et al. (2006) is to conduct "convergence coding". Instructions included:

Identify themes from each data source. Compare the findings to determine the degree of convergence of (a) essence of the meaning and prominence of the themes presented and (b) provincial coverage and specific examples provided in relation to the theme. Characterize the degree and type of convergence (Farmer et al., 2006, para. 383).

Choosing predefined coding themes helps to reduce both subjectivity and the proliferation of codes (Lacy et al. 2015, Stemler, 2001). Based on these recommendations initial codes were chosen from the major categories of the WHO's (2010) major categories for addressing the quality of life for people with disabilities:

health, livelihood, education, social and empowerment. The data was collected over a span of twelve months grounded in the suggestions on mixed methods by Bengtsson (2016); Creswell (2015); Creswell, Klassen, Plano-Clark, and Clegg Smith (2010).

In an effort to maintain the exploratory capacity of the study coding themes were added if they appeared as significant concepts or themes in the material even if they could have fit under one of the predefined categories. As such there nineteen themes for which the materials were coded: ableism, acceptance, community inclusion, disability technology, education, empowerment, health (including mental health and eugenics as subcategories), identity, intersectionality, justice, language, livelihood, parenting, perception, representation, social, and travel. Once the data was grouped and thematically coded Farmer et al. (2006) want the type of concurrence or nonconcurrence of coding themes across the three data sets characterized as: agreement, partial agreement, silence, or dissonance.

Chapter 4: Results

Part II of Triangulation Protocol

Step 3: Convergence Assessment

The next step in Farmer et al.'s (2006) triangulation is to evaluate the frequency of themes and concurrence or nonoccurrence of themes and across data sets for a "global assessment" of convergence. The first comparison was identified themes across sources.

Themes across categorized sources: Most themes shared a significant degree of partial agreement in that all four of the categorized sources addressed the theme with exception eight themes where there were no materials attributed to government sources, so those were determined to be silent on the theme. Only one theme was determined to be in full agreement. The nineteen themes can be divided roughly into groups of five to analyze results.

Table 1

Codes and Agreements

Codes	Agreement	Partial Agreement	Silence	Dissonance
Perception		1300		
Community Inclusion		508		
Empowerment		501		
Livelihood		349		
Education		259		
Justice		208		
Parenting		167	1 (Gov)	
Health		166		
Intersectionality		166	1 (Gov)	
Social		151		
Ableism		123	1 (Gov)	
Disability Technology		120		
Identity		109	1 (Gov)	
Travel		95		
Acceptance		40	1 (Gov)	
Mental Health		39	1 (Gov)	
Eugenics		25	1 (Gov)	
Language				151
Representation	348			

All sources addressed the theme of representation. It is widely agreed upon that the disability community is underrepresented in a wide range of daily living aspects including with the most noted aspects being the livelihood category (Beatty, Baldridge, Boehm, Kulkarni, & Coletta, 2018; Erickson, Lee, & von Schrader, 2017); Faculty Report 2016; Oregon State University, 2018), media representation (Ruderman Foundation 2017), and public service, (Ellison, 2018; National Council on Independent Living [NCIL], 2018; Powell, 2018).

Perception ranked as the highest theme upon which there was partial agreement, followed by community inclusion, which dealt predominately with people desiring access to services and places. Of the categories that WHO (2010) listed as important to address for people with disabilities three of the five where among the most frequent themes based upon sources. The theme that was determined to have dissonance in it was language.

Table 2

Codes and Sources

Codes	Corporate	Government	NGO & Nonprofit	Personal	Totals
Perception	851	13	213	223	1300
Community Inclusion	372	3	88	45	508
Representation	348	3	54	73	478
Empowerment	287	6	154	54	501
Livelihood	270	13	52	14	349
Education	221	1	29	8	259
Justice	152	7	35	14	208
Health	124	1	29	12	166
Social	108	4	23	16	151
Parenting	107	0	50	10	167
Disability Technology	106	5	5	4	120
Intersectionality	80	0	48	38	166
Travel	73	1	18	3	95
Language	61	2	30	58	151
Identity	54	0	16	39	109
Ableism	45	0	26	52	123
Mental Health	25	0	11	3	39
Acceptance	24	0	11	5	40
Eugenics	19	0	1	5	25
	3327	59	893	676	4955

Themes that were in the middle of the groupings were most often to be discussed by nonprofit or nongovernmental organizations. Individuals or advocacy groups were the most likely to address the issues of parenting, intersectionality, ableism, and identity. The themes of disability technology, and travel were mostly covered news organizations. Travel because during this time legislation regarding airline wheelchair tracking was undergoing significant changes (Duckworth 2018; McBride, 2018; Schaefer, 2019). Health and its subtopics of mental health and eugenics, as well as disability technology were covered by individuals and news corporations. Acceptance was focused on advocates and individuals who argued that the concept of acceptance is more important than awareness, especially when it comes to "awareness" months often raised by various advocacy groups (Dickrell, 2017; Huemann 2017). The argument being that acceptance does more to include people disabilities than awareness. When examined based on sources themes appeared most frequently in the corporate categorization with 67% of the themes being in that source category.

Nonprofit and NGO categorized data were the next most coded at 18% with data coded as a person source at 14% and government at 1%. Table 2 provide a breakdown of themes across sources.   The table identifies how many times a particular theme was coded across sources. Sources categorized as corporate have significant frequencies of all themes. Nonprofit and NGO categorized sources had the next highest frequency of themes. The number of coded themes dropped measurably between the categorization of personal sources and government categorized sources. The absence of government categorized sources on 38% of its coded themes, and relatively low numbers of coded

themes as compared to the other categorized sources is significant. Particularly as many of these themes are directly or indirectly impacted by government policies.
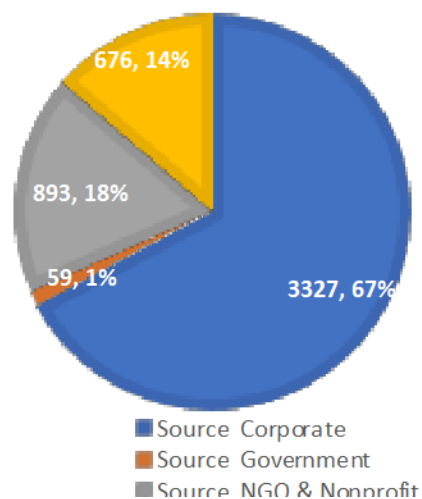
CODE PERCENTAGES BASED ON SOURCE

Figure 2. Codes and Percentages

Thematic assessment across categorized data sets

Across all three data sets, Facebook Posts, News Articles, and Website Pages, there was partial agreement across all themes. For the purposes of this research data that came from newspaper websites was categorized as news articles. All other website data was categorized as website pages. The only exception was the noted silence on the theme of ableism in the News Articles data set. Ableism was most likely to be found as the topic of discussion among disabled advocates and Disability Studies groups in Facebook postings or website pages like "The Mighty". In concurrence with the theme findings from the source categorizations perception, empowerment, livelihood, representation and education came where the most frequently coded themes across data sets; here again the prioritized topics set out by the WHO (2010) were included. Justice, social, health, community inclusion, and disability technology were the next set of frequently coded

themes. The next group of coded themes included parenting, language, intersectionality, travel and identity. While the least coded themes across data sets were travel, identity, ableism, acceptance, mental health and eugenics. Looking specfically at the separation of codes by data set website pages accounted for the largest data set, followed by news articles, and Facebook posts. Since all of the data was collected from Facebook, it is important to take notice of the intent of many groups to use Facebook as a way to desseminate links to websites and news articles as much as use Facebook as community forum. Website pages made up 62% of the data collected, news articles 31%, and actual Facebook posts only made up 7%.

Table 3

Codes and Data Sets

Codes	Agreement	Partial Agreement	Silence	Dissonance
Perception		618		
Empowerment		287		
Representation		275		
Livelihood		201		
Education		165		
Justice		135		
Social		100		
Health		97		
Community Inclusion		95		
Disability Technology		95		
Parenting		95		
Language		89		
Intersectionality		76		
Travel		75		
Identity		66		
Ableism		54	1 (News)	
Acceptance		41		
Mental Health		27		
Eugenics		11		

Table 4

Codes and Agreement Level

Codes/Data Sets	Facebook Posts	Website Pages	News Articles	Totals
Representation	47	432	130	609
Empowerment	21	154	112	287
Livelihood	8	108	85	201
Education	3	104	58	165
Community Inclusion	13	61	84	158
Justice	7	56	72	135
Social	1	75	24	100
Health	4	57	36	97
Disability Technology	2	52	41	95
Parenting	3	74	18	95
Language	14	61	14	89
Intersectionality	13	47	16	76
Travel	0	37	38	75
Identity	15	43	8	66
Ableism	14	40	0	54
Acceptance	5	30	6	41
Mental Health	3	14	10	27
Eugenics	1	5	5	11
Totals	174	1450	757	2381

Data and Source Type Analysis

The total number of materials gathered in the twelve month span was 1,926 individual pieces. When data set types were compared with source types there were a total of eighty data pieces categorized as a personal source with the largest data set in that source type being the website pages, followed by Facebook posts and just one news article. Data categorized as NGO & Nonprofit had similar results in data sets. Materials categorized as coming from a government source were the smallest across all the data sets with website pages totaling twernty-seven, zero Facebook posts and a single news article. In contrast data categorized as corporate source had the largest results in websites at 761 and news articles at 569 and scant Facebook posts at 6.

Code percentages based on data set

191, 7%

848, 31%

1726, 62%

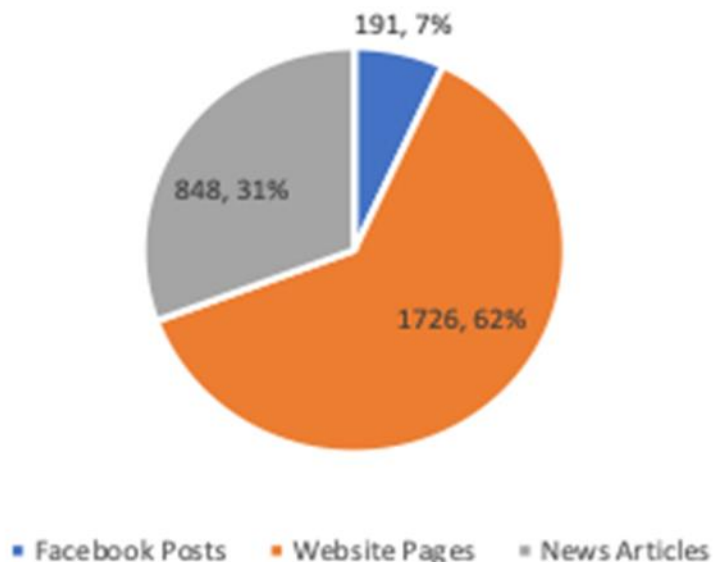- Facebook Posts   - Website Pages   - News Articles

Figure 3. Code and Data Source Percentage

According to the triangulation protocol laid out by Farmer et al. (2006), the next step is the completeness assessment. In the completeness assessment, later referred to in their paper as completeness comparison, each of the data points are compared to each other for an overall sense of data congruence.

In this step, we aim to broaden the range of findings relevant to the research question to ensure completeness in perspective and in the ways in which a theme is characterized. Based on the convergence assessment, it is evident that there are many theme areas and examples in which the two data sets agree and confirm core themes (Farmer et al., 2006, p. 388).The protocol also suggests using verbatim excerpts from the data as examples for the similarities or unique topics among data sets.
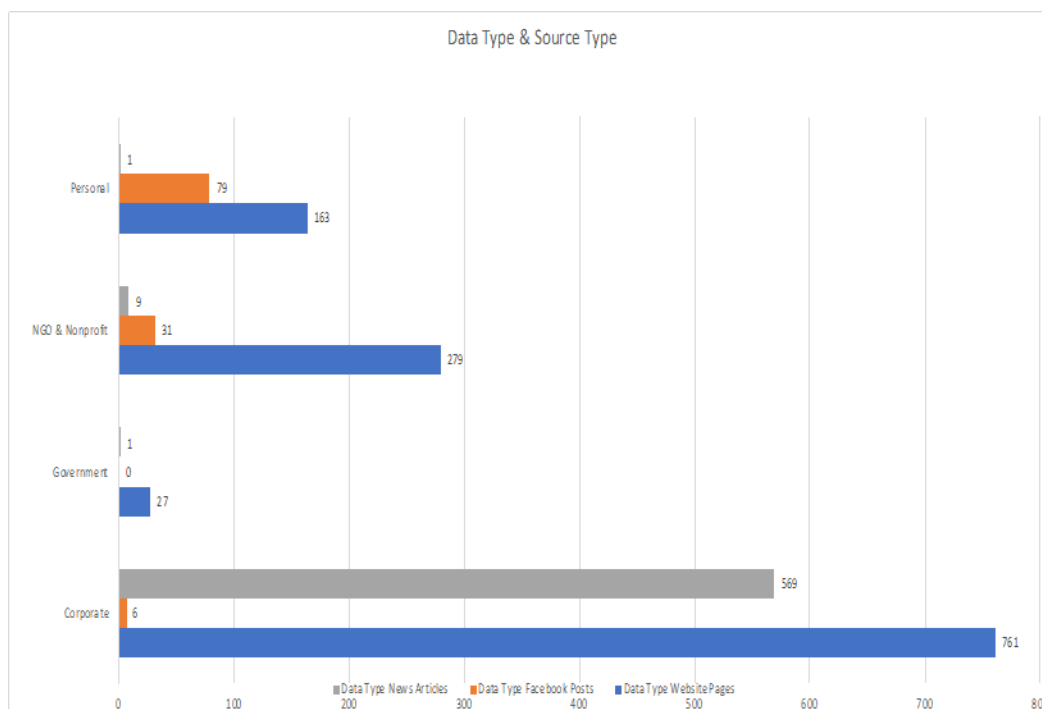
Figure 4. Data and Source Breakdown

Step. 4: Completeness Assessment

  Similarities across data set type and source type. The theme that came up most frequently throughout all material was the concept of perception. Perception was most often the theme that was a secondary code. For example, an article on women with disabilities' employment coded as "livelihood, intersectionality, and perception because part of the article said

> My experiences—being denied employment and facing financial planners who
>
> make false assumptions about my income status and earning potential because of
>
> my disability, for instance—prompt my suspicions that triple jeopardy is working
>
> against many African-Americans with disabilities," added Dr. Walton
>
> (Appelbaum, 2019, para. 11).

The article's main subject matter was women with disabilities employment rates, however because the article included the voice of a black women with a disability it

coded with "intersectionality". Since the interviewee specifically said the phrase "false assumptions" it coded as perception as well.

Another example was from Major League Baseball's decision to discontinue the phrase "disabled list". This article focused on the use of the term "disabled", so its initial coding was "language". The second paragraph said:

> The principal concern is that using the term 'disabled' for players who are injured supports the misconception that people with disabilities are injured and therefore are not able to participate or compete in sports," Jeff Pfeifer, MLB's senior director of league economics and operations, wrote in a memo to clubs in December (Bogage, 2019, para. 2).

Because the word "misconception" was used the article coded as perception. The perception of people with disabilities impacts every facet of their lives. As such it is meaningful that the topics selected by the WHO (2010) were also significantly coded themes, many of which the government has direct impact on. Healthcare is still a widely contested federal topic and was one of the major sub-themes of empowerment because the WHO defined empowerment as including "advocacy and communication" and "political participation". The topics of education, community inclusion, livelihood and to a much less acknowledged degree parenting.

Public Accessibility coded as community inclusion is still an issue even with ADA being close to thirty years old. For the general population, public accessibility often conjures images of ramps into buildings, but as the sampling from the data shows, public accessibility is a wide-ranging issue. Examples from the data provide insight into just how varied public accessibility issues are.

Example 1. With Twitter, you don't have to leave your house in order to connect, and organize, and educate. And as such, it's accommodating for people with disabilities that can face acquiring transportation to meet up with other like-minded individuals. Like going to a meeting; that takes more than just takes effort, it takes energy, but also is the transport even there? …And Twitter also has some really cool features like as far as accessibility goes, they even offer a way to embed image descriptions into a photograph so that people with visual disabilities can know what's going on, and what's being depicted in a scene or a picture (Wilson-Beattie, 2018, para. 8-9).

Example 2. OKLAHOMA CITY - John High visits the capitol often. He advocates for the rights of those with disabilities. But. now, he's fighting for his own. "I am being discriminated against, since I'm in a wheelchair, an electric wheelchair, I'm being discriminated to be able to go there," High said. He was going to the House Gallery to watch lawmakers, but staff quickly turned him away at the door. The floor sergeants told High, because of his motorized chair, he can't watch session from the gallery seats. "Is that right?" High said. The wheelchair lifts in the capitol have a capacity limit of nearly 500 pounds. High and his chair exceed the limit. "I have a right, as a citizen of this state and as a person with a disability, I have the right to participate on an equal level as much as anybody else," said Jeff Hughes. Hughes is the executive director of Progressive Independence, a group that fights for full inclusion for people with disabilities and their rights under the American Disabilities Act. "28 years after the fact, and we're sitting here arguing about a lift," Hughes said. Speaker of the House Press Secretary Jason Sutton tells us an oversight committee will look into the cost and present ideas to make the gallery more ADA compliant. "Certainly, we recognize it as a

problem, and we want to make sure that we accommodate those who are handicapped and want access to the chamber and the floor," Sutton said. But, High said he's given capitol leaders enough time already. "This has been addressed now for five years. This is my third time giving them enough time to fix it," High said. We're told ADA regulations said those lifts are actually supposed to accommodate up to 750 pounds. High said he's now considering filing a lawsuit not for the money but for equality. In the meantime, officials at the capitol have told him he can watch the debates on a television in front of the chamber doors (Gibbs, 2017, para. 1-16).

Example 3. To the average nondisabled person, a plastic straw seems like a nice-to-have accessory, but for many disabled people, plastic straws are a necessity. Straws are an access issue, because without them I wouldn't even be able to take a drink of water in most public places. Sure, reusable straws exist, but arguing (as many people have) that those of us who need straws should take on the responsibility of carrying them everywhere misses the larger point. The reality is access is not a personal issue; it's a societal issue. Accessibility is not an individual problem, but rather something everybody needs to be invested in. When I can't get into a building because there's no ramp, I'm not the problem. The building is the problem. It's not on me to carry around a metal or wooden ramp, or magically learn to walk upstairs; it's the building that needs to change. Everybody has access needs, but what most nondisabled people take for granted is that society is structured to meet their access needs without a second thought. Nobody would build a three-story building and forget to put the stairs in, because then that building would be inaccessible to nondisabled people who need the stairs to get from floor to floor. Yet, we still build buildings without ramps, nearly 30 years after the passage of the

Americans with Disabilities Act (ADA), a law that guarantees equal access and civil

rights for disabled people. We still expect disabled people to learn to fit into the

nondisabled world, instead of coming up with better solutions for everyone (Hitselberger,

2018, para. 2-4).

Much of the discussion around these topics focused on the fact that all but

parenting is covered under some aspect of the ADA the enforcement of legally

established for people with disabilities is lacking teeth because of the public perceptions

of disability is one of burden and outcast.

People could literally make it easier on everybody if they'd stop viewing

disability as a problem and start viewing it as an identity, but we're not there yet

(Consider It, 2018, 18:00).

During one of the federal rounds on the Affordable Health Care act the phrase

#Iamapreexistingcondition (#iamapreexistingcondition, [ca. 2017]) began appearing on

Facebook and Twitter. People would discuss what having a preexisting condition was

like, why being covered by insurance was so important and include contact information

for their federal representatives, encouraging people to call them and request that the

representative take action to protect their coverage.

There was also considerable news coverage involved in the theme coded as

justice. At the height of the reporting of policing activities in the Black community there

was significant coverage about the dangers the disabled community faces when

interacting with police and the justice system.

Example 1. The suit alleged the brutality was "magnified for people with

disabilities." Nationally, an estimated 33 to 50 percent of those killed by police have a

disability, with approximately 25 percent of people killed having a mental illness, the suit alleged. The problem also extends to police use of nonlethal force, including with Tasers, the ACLU contended. "The City of Chicago deploys officers armed with guns and Tasers but not deployed with critical de-escalation skills, and in doing so subjects residents, police officers, and bystanders to harm," the suit alleged. "When people with disabilities are subjected to CPD's use of force, the role that their disability played is often either ignored or cited to blame the victim," (Meisner & Gorner, 2017, para. 3-4)

Example 2. Darren Rainey, an inmate at the Dade Correctional Institution in South Florida, was serving a prison sentence for cocaine possession in June 2012, when guards took him out of his cell, forced him into a shower stall and locked the door.

From the outside, they turned the water on scalding hot, possibly as high as 180 degrees, then walked away. As the narrow room filled with steam, Rainey, a 50-year-old with schizophrenia, could be heard screaming, "I can't take it anymore," a fellow inmate would later say.

After nearly two hours, the guards went in to check on him. Rainey lay dead on his back in three inches of water. His skin had reddened and begun to peel off, flecks of it floating next to him, as the Miami Herald reported (Hawkins, 2017, para. 1-3).

Example 3. Leibel was walking down the sidewalk in an affluent part of Buckeye, Arizona. He first appears on the body cam video as he's shaking a string in a mild rhythmic motion with his left hand. Officer David Grossman of the Buckeye police department, steps out of the car and approaches the boy, asking him what he's doing. "I'm stimming," he says. "I stim with a string." Within a few minutes, Grossman has Leibel down on the ground, cuffed. "I'm OK, I'm OK," the boy says to himself, but

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eventually starts to scream. Later, other officers would arrive, find Leibel's caregiver nearby, and restore order. Leibel suffered bruises and abrasions. Grossman, reportedly a DUI recognition expert, has claimed in his report that he thought the boy was on drugs. Buckeye Police did not respond to requests for comment (Perry, 2017, para. 7).

According to the Washington Post database in 2017, 987 fatalities were caused by police with one quarter of those victims found to be mentally ill. During this time the Alaskan state legislature proposed a bill that would have required police officers to received special training in dealing with people with disabilities. The bill died in Senate committee (Buxton, 2017). David Perry and Lawrence Cater Long conducted a study for the Ruderman Foundation (2016) conducted a study of media coverage of police use of force on people with disabilities. The study which occurred from 2015-2017 said in part:

Twenty-five years after the U. S. Congress passed the Americans with Disabilities Act, notions of disability continue to evolve. An increasingly powerful set of concepts, they push us to redefine how to build an inclusive society that is accessible to all.

When disabled Americans get killed and their stories are lost or segregated from each other in the media, we miss an opportunity to learn from tragedies, identify patterns, and push for necessary reforms (p. 2).

The needs of disabled people aren't special. There is nothing special about not wanting to be shot. What disabled people seek are the same things (employment, education, access, consideration, respect, etc.) that non-disabled people likewise desire. The obstacles faced by disabled people, though, too often go unseen. The language used to report issues that confront disabled people—especially issues linked to injury and death—should reflect that disparate reality (Meisner & Gorner, 2017, para. 9-11).

One theme that came up through all data sets that was not directly connected to the WHO (2010) or ADA was the subject of disabled parenting. Attention to this topic is driven by NGOs like Rooted in Rights and the Disabled Parenting Project. State laws vary as to whether people with physical and intellectual can retain custody of their children. As of 2019 only eighteen states have passed laws protecting the rights of physically and intellectually disabled parents (National Research Center for Parents with Disabilities [NRCPD], 2019), another eight states have legislation pending. Again, perception seems to be an underlying factor in acknowledging and protecting the rights of disabled parents. Mary Hull, a mother with Charot-Marie-Tooth - a genetic neurological condition, created a television documentary that chronicled the lives of disabled parents.

Example 1. My theory is that parents with disabilities are often not represented in the media because there is still a societal view that people with disabilities shouldn't be parents…I found the most common challenge each parent experienced happened in the community. They came from assumptions from strangers that our children must be looking after us, or that disability is inherently something negative, or horrible. Through more representation of people with disabilities, I feel we as a community are breaking down some of these stereotypes and beliefs. Now, more than ever, there is talk about diversity, about sharing our stories, varied as they are (Hull, 2018, para. 5, 14-15).

Example 2. My experience as a blind mom is that people often assume that if you have a disability you can't take care of yourself, and by extension, that you can't take care of a child. Some folks even lay their ableist beliefs right at my daughter's feet, saying things to her like, "Oh, it's so nice that you can help take care of your mom" when we are out on walks. Sorry, folks, there's no role reversal in my household. Comments

like these show how deeply embedded ableism is in our culture. My daughter and I go on

walks to the park together just like other families do, she just wears spirit bells and a GPS

tracker so that I can tell where she is. This is called "adaptive parenting." There's not

enough awareness about what is possible when disabled parents are provided the supports

and services they need. The National Council on Disability's Parents Rights Task Force

is currently working to get federal legislation passed that would ensure training to family

court system employees about adaptive parenting and the rights of disabled parents. This

is badly needed as children of parents with disabilities suffer disproportionately high rates

of involvement with the child welfare system (Lorenz, 2017).

     Example 3. The notion that people with disabilities should not be parents dates

back to the eugenics movement in the early 20th century, when people with disabilities

and others who were deemed "unfit to procreate" were forcibly sterilized. Shockingly, in

the notorious 1927 Buck v. Bell case, the U.S. Supreme Court ruled that it was

constitutional to forcibly sterilize women with disabilities. This disturbing ruling led to

more than 30 states implementing laws that allowed for forced sterilization. By the

1970s, an estimated 70,000 Americans, many of whom had disabilities, were sterilized

against their wishes. Horrifyingly, Buck v. Bell has never been overturned —meaning it

continues to be viewed as good law. Today, eugenic ideologies manifest themselves

through discriminatory policies and practices that discriminate against parents and

prospective parents with disabilities. As Fabbrini and Ziegler's story demonstrates,

parents with disabilities often encounter bias and speculation by the child welfare system.

In fact, longstanding research indicates that parents with intellectual or psychiatric

disabilities have their children removed by child welfare agencies at rates as high as 80

percent. Parents with physical disabilities as well as those who are blind or Deaf also have disproportionately high rates of involvement with the child welfare system and termination of parental rights.

Similarly, parents with disabilities are less likely to be awarded custody or visitation rights of their children in family court. Because of the known discrimination by family courts, some parents with disabilities have remained in abusive relationships out of fear they would not be granted access to their children if they left. This is especially disturbing because women with disabilities are 40 percent more likely than nondisabled women to experience intimate partner violence (Powell, 2017, para. 6-9).

The similarities between themes in the data sets is important, but only tells part of the picture of the data. The next portion in Farmer et al.'s (2006) completeness assessment in triangulation protocol is to examine unique themes or issues raised in the data.

Unique findings across data set type and source type

There were several themes that while less prominent in the data still merit some analysis. It is also what was not there that was worth spotlighting because the absence of data on topics from a particular source can have meaningful repercussions. It is the silence that should be addressed as the first unique finding.

Silence. Out of the nineteen themes coded for source type there were only fifty-nine themes coded in the government source type. Of those fifty-nine theme codes there were zero codes recorded in the areas of parenting, intersectionality, identity, ableism, mental health, acceptance, and eugenics. There was no government sourced content to analyze on 42.1% of the themes. When comparing source type with data type,

government source type material accounted for 1.45% of the total pieces of 1,926 pieces content collected for analysis.

It is worth investigating the themes displaying government silence where government has influence over to one degree or another. Several of the issues lacking in government sourced material were addressed specifically by disabled rights advocates and they are in the process of making legislative and policy recommendations about many of them as well as adding to the public discourse on the topics.

Parenting. As Powell (2017) mentioned local governments currently have jurisdiction on parental rights, and on the national level there were nationwide trends of policies that forced sterilization on women with physical and mental disabilities up into the 1970's (Reiter & Walsh, P.C., 2018). At present according to Ne'eman (2018) the Washington State legislature has a bill before it that is intent to streamline the process for guardians to request involuntary sterilization for wards in their care. Advocates and the ACLU are concerned the wording of the bill would make it easier to sterilize people with disabilities against their will.

Ableism. The themes of ableism, and the silence of government sourced materials about it serve as both a theme in its own right and secondary theme for other concerns brought forth by non-profits and disability advocates. In particular they tie these ideas to discrimination and abuse. The New York Center for Disability Right defines ableism as:

> a set of beliefs or practices that devalue and discriminate against people with physical, intellectual, or psychiatric disabilities and often rests on the assumption that disabled people need to be 'fixed' in one form or the other. Ableism is intertwined in our culture, due to many limiting beliefs about what disability does

or does not mean, how able-bodied people learn to treat people with disabilities and how we are often not included at the table for key decisions (Smith, 2017, para. 1).

The National Center for Community and Justice (2017) points out that the ADA broadly defines disability as issues of functionality rather than medical diagnosis. However, in order for a person to qualify for SSD or other government services they must be medically identified as having a disability. This matters when it comes to crimes committed against disabled people. Systematic ableism seeps into this in terms of long-term care.

> Long term care systems that make it administratively easier to find everyday care for disabled people in nursing homes and institutional settings than to assemble the services needed to live independently in the community. This is a very potent example of Systemic Ableism, in that it literally dumps people into more restricted, hemmed-in lives, not by necessity, but by habit and bureaucratic inertia (Disability Thinking, 2014, para. 5).

Many disabled people in or out of care institutions are reliant on caregivers, and according to the Southern Poverty Law Center (SPLC) (2018) reports that there is widespread violence against people with disabilities by their caregivers. Laretta Garcia (2018) writes about the number of times her mother had threatened her life by the time she was twelve years old. Upon finding that Garcia had snuck into candy one day her mother flew into a rage.

> I can't deal with you anymore. I gave you life, and I can take it away." She presses the blade into my throat. At this point I stopped breathing, as a choice.

She keeps saying that phrase. I can feel the teeth of the blade digging deeper into

my throat. All I can think is, at least my little brother won't have to see this

(Garcia, 2018, para.7).

Mental health. Systemic disenfranchise of disabled people through lack of choice

or abuse is just one of many issues. When it comes to mental health, and suicide the

waters muddy severely. Here again governments, both local and federal have varying

rules and laws about involuntary commitment or forced treatment by health professionals

and law enforcement. Effective April 1, 2018 Washington State gave law enforcement

the power to involuntary commit people in mental health crises (Washington State

Hospital Association, 2018). Given the Washington Post statistics on the death rates of

people with mental health issues during police interactions and the fact that police aren't

trained mental health professional such legislation seems ill-advised especially given that

people with disabilities are more likely to have depression than those without.

Determining the rates of depression and suicide in people with disabilities is

difficult because they are an under-served population when it comes to mental

health and suicide prevention studies. In simply trying to find statistical information for

this section there was one study that said the rates of depression and suicide in the

disabled population in the U.S. were as high as 30% (The Shaw Mind Foundation

[Shaw], n.d), while another study said that the rates of depression in the typical

Americans is 5% (Thompson, 2002) at any given time and the rate of depression in

people with physical and intellectual disabilities is twice as high as the average for non-

disabled people. Three other sources concurred that the rates of depression and suicide

in disabled populations are higher but did not give statistical information to back the

claim (Gill;1985, Suicide Prevention Resource Center [SPRC] 2018, Weiss 2017). All of

the sources did agree that depression and suicide is higher in people with disabilities

because they face mobility issues, accessible care issues, social barriers and social

isolation issues. Because depression and suicide are underserved issues in the disability

community a program called the Live On Movement was established to give people with

disabilities a forum to discuss the relationship between disability, depression and suicide.

On platforms like Facebook and Twitter under #LiveOn people share stories of their own

issues and often provide support. The movement also tries to raise the public profile of

people with disabilities as a way of combating the stereotypes of disabled people.

    Assisted suicide. Carol Gill (1985) has continued to advocate for mental health

services and suicide prevention access for people with disabilities since she first wrote on

the issues. What often comes from those conversation is the option of assisted suicide.

    Disability, in relation to suicide, is something that is very hard to find statistics on

    and it is not a new phenomenon. In an article published by Carol J. Gill it was

    noted that it was ironic that so little suicide research has been conducted on the

    behalf of people with disabilities, since there are so many legal and medical

    decisions made about disability and the management of intentions to die. Carol

    Gill was referring to assisted suicide, a twist that makes all the difference. There

    is a mixed message suggesting that people with disabilities are only visible on the

    issue of suicide when others such as judges and doctors are making the decision

    for us. In addition, this reinforces the idea that disability is a legitimate reason to

    desire death; this writer certainly disagrees with this idea (Weiss, 2017, para. 4).

Assisted suicide has been legal in some European countries for decades. Controversy over the procedure is ongoing. In the Netherlands a physician was cleared of any wrongdoing after telling a family to hold down a woman with dementia while he administered a lethal drug cocktail. The woman had expressed to her family that she wanted to die when the time was right. She woke up despite being given a sedative before the cocktail was introduced to her system. At that time she expressed that she did not want to die, but the doctor "had determined the time was right because of a recent deterioration in the woman's condition" (Roberts, 2017, para. 5). It was determined that the doctor had acted in "good faith".

The movement to make assisted suicide legal within the U.S. has been gaining traction for years. As states seek to legalize it disability advocates seek to stop it. Not Dead Yet is national grassroots disability organization that opposes assisted suicide on the grounds that assisted suicide is more a disability rights issue than a palliative care issue. The reasons Not Dead Yet give for opposing assisted suicide is that physicians are the gate keepers of the procedure and often misjudge the quality of life for those with chronic illness or disability.

> In judging that an assisted suicide request is rational, essentially, doctors are concluding that a person's physical disabilities and dependence on others for everyday needs are sufficient grounds to treat them completely differently than they would treat a physically able-bodied suicidal person. There's an established body of research demonstrating that physicians underrate the quality of life of people with disabilities compared with our own assessments (Gerhart, K. A., Kozoil-McLain, J., Lowenstein, S.R., & Whiteneck, G.G. (1994). Quality of life

following spinal cord injury: knowledge and attitudes of emergency care providers. Annals of Emergency Medicine, 23, 807-812; Cushman, L.A & Dijkers, M.P. (1990). Depressed mood in spinal cord injured patients: staff perceptions and patient realities, Archives of Physical Medicine and Rehabilitation, 1990, vol. 71, 191-196). Nevertheless, the physician's ability to render these judgments accurately remains unquestioned. Steps that could address the person's concerns, such as home care services to relieve feelings of burdening family, need not be explored. In this flawed world view, suicide prevention is irrelevant (Not Dead Yet, 2019, para. 8).

Their concerns played out in events in the Netherlands, they are worried that assisted suicide will open the door to involuntary euthanasia.   Not Dead Yet is not alone in those concerns. Seven states and the District of Columbia have legalized physician assisted suicide (ProCon.org, 2017). Connecticut has a bill before the state legislature to make assisted suicide legal there. Attorney and disability rights activist Lisa Blumberg takes exception to much of the bill's phraseology.

Let's not be confused by double speak. The bill (HB 5898) that the Connecticut legislature is poised to consider has nothing to do with "aid in dying." Aid in dying is palliative care to improve the quality of a person's remaining life. The World Health Organization views such care as a human right. The bill would not expand desperately needed access to palliative care or expand patient autonomy – patients already have the right to refuse any type of treatment. Instead, the bill concerns the authority of doctors. It sets forth the circumstances under which a doctor could actively prescribe lethal drugs to directly cause the death of a

supposedly willing patient without fear of liability. If the selective writing of

lethal prescriptions was a valid medical practice, as proponents assert that is, there

would be no reason for laws to immunize medical professionals from suffering

any consequences from doing so. What is being proposed in HB 5898 would

amount to a radical change in medical culture. Causing death could be viewed as

an option in the "care" of some patients (Shadenberg, 2019, para. 2-3).

Eugenics. For many in the disability community the issues of parenting,

institutionalized care, abuse, sterilization, assisted suicide, are deeply rooted in

eugenics. The United States has a sorted history with the topic. Much of the eugenics

research done in 1920's in the United States was the basis off which many state laws

were formed, including the law that would later become the case for Buck v. Bell in

1927, which as Powell (2017) mentioned as never been overturned. In 1920's the

Eugenics Record Office (ORE) was run by Charles Davenport, a zoologist, who hired

H.H Laughlin as the superintendent of the ORE. Laughlin's work the 1922

publication *Eugenical Sterilization* changed the legal landscape for people with

disabilities and people of color. His publication included the drafting of a "model law"

for compulsory sterilization that was the bedrock of forced sterilization programs

throughout the country. According to Davenport, Laughlin's "book on sterilization is

recognized as the standard." In 1930, Laughlin comments about the U.S. Supreme Court

upholding a Virginia sterilization statute as, "the establishment of the eugenical authority

of the state … [enabling] the prevention of hereditary degeneration by a method sound

from the legal, eugenical and humanitarian points of view. … It is now possible for any

state, if it desires to do so, to enact a sterilization statute." (Farber, 2008, para. 8).

Though the practice of sterilization was condemned by the scientific communities of the U.S. and England in 1936 by then "60,000 forced sterilizations had been performed" (Farber, 2008, para. 7). Laughlin's work would be the basis for Nazi experimentation during WWII. That experimentation began on German's with disabilities who were taken from church run asylums by the German government.

Physicians were given authority to administer "mercy death" to those they considered "incurably sick" (Proctor, 1987), the German government says a total 200,000 Germans (Das Budensarchiv, 2018) were put to death in this way. They are not considered an official part of total holocaust deaths because their deaths occurred beforehand. Today the concept of eugenics is still being discussed just in different ways. It comes under the phrase "genetic testing". A genetic education website run by pre-med majors offers the public this information, it said,

> As research continues to uncover new disease-causing mutations, it becomes increasingly possible to stop the transmission of certain heritable diseases. In the long term, this may lead to complete eradication of diseases like Down Syndrome, cystic fibrosis, and hemophilia. However, some wonder if modern day attempts to eradicate hereditary disorders equate to eugenics. One complication of genetic testing for the purpose of disease eradication is that, in practice, a particular ethnic group will likely be involved due to shared ancestry. For instance, Tay-Sachs disease is significantly more common in certain Jewish communities. Tay-Sachs is a genetic disease that causes a deterioration of mental and physical abilities and results in death by age four. Eradicating Tay-Sachs will require screening all individuals in the affected population. However, a public campaign to test all

individuals of Jewish descent for Tay-Sachs carrier status may for some recall the racist motivations of eugenicists in the early 20th century, particularly those associated with Nazi Germany. Also, racial stereotypes or biases may be reinforced if genetic testing performed on individuals of an ethnic group reveals a predisposition to a particular disease or condition. Using modern genetic technology, prospective parents can be prescreened to determine their carrier status for certain diseases. Preimplantation genetic diagnosis following in vitro fertilization allows parents to select embryos that are free of disease. Additionally, prenatal genetic testing can provide a lot of information to parents about their unborn child. These technologies make more informed decision-making possible, but some are concerned about a shift in the way we view family and parenting. Parents who want to have a child without pursuing genetic testing may feel guilty if the child is born with any health problems. Additionally, some are concerned about what an overemphasis on eliminating disabilities in unborn children will mean for people who already have the disability. The most significant difference between modern genetic technologies, that some view as eugenic, and the historical use of eugenics is consent. Today, individuals pursue genetic testing by choice. An individual can never be forced into testing or be required to take action, such as sterilization, based on the results of a genetic test. Individuals differ in their views on genetic testing in relation to reproductive decision-making and possible eugenic motivations, but at least today parents have the choice to use the technology or not (Genetics Generation, 2015, para. 1-4).

While supposedly judgment free in their offer for information the Genetics

Generation website used the word disease to describe people with Down Syndrome. The

choice of such deficit-based language (Mertens, 2009) by groups interested in

healthcare perpetuates the idea of disability as something to be fixed, this is why eugenics

is still of prime concern for disabled people and advocates. The group is also displaying

ignorance in not acknowledging that forced sterilization is still legal.   People with Down

Syndrome are actively campaigning to not be screened out of existence. In response to

genetic screening nonprofit groups in the U.S. UK and other countries have started the

#DontScreenusout campaign. According to the campaign website 90% of babies

prenatally diagnosed with down syndrome are aborted. In 2017 a CBS report called "On

Assignment" reveled that Iceland has almost completely eliminated Down Syndrome

from the population through prenatal screening. Parents of children with Down

syndrome responded fiercely to the report. Conservative columnist George F. Will,

whose forty-year-old adult son Jon Will has Down Syndrome, called the elimination an

acceptable genocide saying

> Now, before Iceland becomes snippy about the description of what it is doing, let
>
> us all try to think calmly about genocide, without getting judgmental about it. It is
>
> simply the deliberate, systematic attempt to erase a category of people. So, what
>
> one thinks about a genocide depends on what one thinks about the category
>
> involved. In Iceland's case, the category is people with Down syndrome (Will,
>
> 2017, para. 2)

Writer Mardra Sikora, whose son has Down Syndrome, said:

Can you imagine what it's like to have your own child's value, as a human being, debated? A world where you regularly encounter the opinion of scientists and doctors who are literally working to eliminate the entire segment of humanity of which your child is a part…and it all happens without public outrage. Even throughout entire cultures (Sikora, 2017, para. 2).

The government, legal, and scientific systems in the U.S. have profound control over the lives of the disabled citizens in this country. Acknowledging that eugenics has played a large part in the systematic discrimination of people with disabilities must happen. It is unsurprising then that the common undercurrents in much of the material were that of mistrust, frustration and fear. For further addressing of these issues see the discussion section.

One of the final analyzing techniques in Farmer et al.'s (2006) protocol is comparing the data findings with outside sources. Farmer et al. used other researchers in their protocol, however they acknowledge along with O'Cathain et al. (2010) that the guiding theories of the research are also good for triangulation. Based on those recommendations the study uses theoretical perspective as the last triangulation point.

Theoretical Comparison

C**omplexity theory**. With nineteen coded themes that have such breadth and depth as they do the perspective of complexity theory elevates the options for viewing the intricacies of disability in America. The confines of the social model of disability and the medical model of disability limit both conversation and transformational options. The medical model posits that the individual is the problem and that the best course of dealing with disability is to (re)habilitate the individual to function as "normal" as possible or to

eliminate disability through science (Generation Genetics; 2015, NCCJ, 2017). Whereas the social model says the problem does not originate with the individual, but the environmental, organizational, and attitudinal barriers in society (NCCJ, 2017). In a thread on Facebook about the medical model on a personal page there was an intense conversation about how wanting treatment options for disabilities is not the same as embracing the "cure mentality", nor they said should they be required to accept the social and physical structures in society as they are "Or that we have to accept a disabling social and infra structure because they only solution is a cure. No, the only solution is a truly accessible world" (Evans, 2018). Johnson (2007) calls complexity theory a "slap in the face to traditional reductionist approaches to understanding the world" (p. 17), and in this case, complexity theory calls out the medical and social models as the reductionist models they are. People with disabilities do not suddenly become "undisabled" because there is wheelchair access into a building. Nor does changing attitudes about disability necessarily change accessibility. Stella Young said:

> I really think that this lie that we've been sold about disability is the greatest injustice. It makes life hard for us. And that quote, 'The only disability in life is a bad attitude,' the reason that that's bullshit is because it's just not true, because of the social model of disability. No amount of smiling at a flight of stairs has ever made it turn into a ramp. Never. (Laughter) (Applause) Smiling at a television screen isn't going to make closed captions appear for people who are deaf. No amount of standing in the middle of a bookshop and radiating a positive attitude is going to turn all those books into braille. It's just not going to happen (Young, 2014, para. 10).

Morgan (1998) goes further in his complex organizational approach. Structures that conduct themselves as both ethnocentric and egocentric are doomed to failure he says. In this case the enthocentric and egoentric ideals come from the ableism entrenched into American society that struggles to see that "is a *natural* [emphasis hers]part of the human condition" (Wilson-Beattie, 2018, para.2). Morgan says the evolution of perspective is necessary to maintain healthy functioning of an organization. Meadows (2008) says systems have the self-organizational capacity to "learn, diversify and complexify" (p. 81). When people with disabilities have to navigate structural ableism that has made enforcing the ADA still a challenge after close to thirty years with the law in place, it is time to find foundational theories that offer people with disabilities more than an either/or choice of viewing disability's place in American society.

Social justice theory. Rawl's (1999) theory allows for acknowledging the structural inequities that ableism, intentional or unintentional, causes for people with disabilities. There is no beneficial inequity for the disabled community, neither is their equal liberty or justice for them. When examining the themes through social justice theory it's easily applicable to much of the data. When issues like institutionalized care, sub-minimum wage, forced sterilization, and legal loopholes, like cost, are built into ADA then there is adequate room to discuss how to address continuing inequities.

In describing the role of conflict practitioners in social and political change Kenneth Cloke (2013) invoked social justice as the basis for working to change systems. He calls the methods behind conflict resolution transformational in their capacity to depart from law and justice and provide equalizing role among the stake holders making

decisions about policy. Mediation he says can actually "subtly seek justice first" (Ch 14, para. 22) through the structure of the mediation negotiating by allowing parties veto power over any part of the process and involving them in all steps of the process from verbal negotiation to written policy or law. The involvement of all stakeholders from start to finish of a decision is what disability advocates have been demanding for a long time. It is why #nothingaboutuswithoutus has found root in social media postings about special education policy, or the affordable healthcare act. Using to Social Justice theory to shed light on the lack of disabled stakeholders in decisions that directly impact them is a necessity.

   Critical disability theory. Critical Disability theory (CDT) acknowledges the short comings of the social and medical models that have long dominated the perspectives on disability in academia and affirms the "multidimensionality" that encompasses disability. However, Critical Disability theory is grounded deeply in the legal standpoints and directly confronts Critical Legal Theory with regard to disability. In both the broad and specific sense, the ADA was an embedded part of much of the data that having as a point of comparison is a pragmatic decision. CDT places itself as a means to spotlight inequity around disability within the law itself, and such so much of being disabled in America relates to having disability documented first medically and then legally or per policy, the use of CDT to transform both discussion and policy around disability is paramount because that is its intent.

    A critical jurisprudence of disability (1) identifies the sources of oppression

    within the law and legal institutions and, by means of that exposure, seeks to

    relieve disabled people from that oppression and (2) identifies the potential

positive role of law and seeks to create law, use existing law and enlist legal

institutions in the struggle for the emancipation of disabled people, which is the

rationale for CDT itself (Hoskins, 2008, para. 3).

Another aspect that CDT addresses directly is that language impacts the

perception of disability. Hoskins (2008) says the theory sees language as "inherently

political" and that

Language carries with it ideological implications which are more or less

transparent. The word disability is used to identify a sub-set of a population but

the fuzzy boundaries which occur with all social categories are nowhere more

contested than with disability (p. 13).

While language as a singular theme was not among the highest codes it is

nevertheless important to look at both the theme and impact of words used to describe

disability because language is "inherently political" and in the case of words like

"retarded" have been both pathologized and medicalized (Vaughn Switzer; 2003,

Nielsen; 2012; Evans, 2018) while also being politicized for the purposes on

legislation and co-opted as a slur. CDT can be seen as a supporting pillar to muted-group

theory

Muted-group theory. Kramarae's (1981) theory posits that dominate groups

control the language used to describe non-dominate groups, in the case of this study that

non-disabled people determine the language in reference to disability and disabled

people.   Included in data gathered was a piece by Noa Zulman (2018) in which it is

explained that the Democratic National Committee coined the phrase "differently-abled"

as a replacement for "handicapped". Among the problems Zulman mentions with this

change in accepted terminology is that not one disabled person was part of that

change. She continues that its counter parts like "special needs" do nothing for people

with disabilities but rather strips disabled people of self-determination and was done to

make able-bodied people feel better about disability.

> For starters, the phrase is awkward and clunky, tripping up the most fluent of
>
> tongues with its self-righteous sing-song. If we are looking for an elegant and
>
> accessible adjective to describe people with disabilities, 'differently abled'
>
> definitely isn't it. Worse than the term itself however, is the way in which it is
>
> spoken. Most often deployed by abled and neurotypical folk, phrases like
>
> 'differently abled' and 'special needs' reek of a patronising smugness that implies
>
> the speaker's supposed allyship (para. 3)

What is more Zulman continues that euphemisms for disability contribute to the

problems disabled people face on daily basis and from society in general:

> Moreover, replacing 'disabled' with these fluffier, feel-good counterparts
>
> contributes to a culture that alienates disabled folk by deflecting the harsh realities
>
> of living with a disability through recourse to a rhetoric of difference and
>
> uniqueness. Instead of having our pain and struggle acknowledged, we are
>
> constantly reminded of our 'untapped' potential and held up as a pinnacle of
>
> inspiration for the masses. This in turn engenders what English philosopher,
>
> Miranda Fricker, terms as 'hermeneutic injustice' whereby the disabled
>
> community have their social experience obscured from collective understanding
>
> due to structural prejudices in society's understanding of disability. The constant

reiteration of our specialness slowly eats away at the community's capacity to

make sense of our experiences, often leaving us feeling guilty and confused.

On a practical level, the adoption of language like 'differently abled' and 'special

needs' within popular discourse has done nothing to materially improve the lives

of disabled, mentally ill, and neurodivergent people. In fact, I would argue that is

has done quite the opposite, reinforcing a medical model of disability that focuses

on individual ability, rather than structural inequality and social support. Perhaps

this is controversial, but I don't believe that disabled folk have different abilities

or needs than anyone else; rather, we face higher barriers to achieving our goals

and meeting our basic needs due to inaccessible institutions, infrastructure, and

ableist societal attitudes (para. 4-5).

There is definitely application for muted-group theory when discussing language

and disability, however language itself has its own complexities and nuances within an

already complex topic. In Zulman's (2018) laments are not hers alone, many others in the

disability community are combating what it seen as ableist language. While fully

supporting the rights of disabled people to self-determination on language it is worth

noting that assertions about euphemistic language are not anecdotal, the Gernsbacher et

al. (2016) study on the use of "special needs" pointedly supported the assertion that the

phrase is not only "offensive" they call it "ineffective" and call out the fact that

euphemisms "occlude uncomfortable topics" (p.1). Person first language has also

become a point of contention with disabled activists preferring the term disabled as both

descriptor and identity along with other words they are reclaiming with most common

reclaimed word being "crip".   Ladau; 2014, Powell;2019, Zulman; 2018 have all written extensively on why "disabled" is preferred among people who also see it as identity.

While academics, nonprofits and parents of disabled children tend to stick with person first language, some disabled people are beginning to use identity-first language. I had an exchange on a Facebook disability studies page after I had finished collecting data, (I remained on the pages as a way to stay up to date and informed on current academic conversational trends), where a self-identified non-disabled disabilities studies instructor told me that using the term disabled to describe myself was wrong. I needed to use person-first language she said, because it was more respectful. As I tend not to use Facebook as an ideological battleground, I did not respond to her immediately. Other disabled scholars however took her to task for being an able-bodied person trying to dictate to a disabled person how to refer to themselves. They were concerned she did not really understand the subject she is teaching.

The exchange left me pondering how right Kramarae (1981) was about dominant groups controlling language. The language used around disability is changing if only in a vacuum at the moment. People with disabilities are leading the change on the language, but the changes seemed confined to activists' circles and like-minded peoples. People who are not part of the political, social, or educational spheres that engage with disability do not seem to be aware that change is even occurring. If people are not aware change is happening is it still happening?

Step 5: Feedback

Farmer et al. (2006) recommend the final phase of the triangulation process be feedback. The feedback should be among researchers, and stakeholders impacted by said

research and given as a direct result of the interpretation of the data analysis done in steps one through four.

Conflict resolution practitioners. While all models of conflict resolution vary in purpose and process the first step in each of them is to invite all parties to name the problem (Bush and Folger; 2005, Moore; 2003, Winslade & Monk, 2000). If we as practitioners were asked to do that in the case of the disability community, what might our answer be if we were asked to get to the heart of the disenfranchisement of people with disabilities? The problem's name is marginalization. In Identifying marginalization as an issue facing their students the University of Syracuse outlines the many ways marginalizing a person or a group can happen. They suggest coping mechanisms for students feeling marginalized and then they go a step further, the university acknowledges that marginalization with continue to occur unless society takes a larger role in ending it. Among the steps they suggest for addressing marginalization many involve self-monitoring techniques for observing biased thoughts, language or actions that we engage in as individuals. Surely, this is the least that conflict resolution practitioners should take. As a community Cloke (2013) is urging us to do more to help our communities live in real and stable peace. Beyond recognizing and addressing our own bias there is room for the application for restorative justice practices as they relate to the disability community and ADA. There is also opportunity for the conflict resolution community to train in and use Feingold's (2016) structured negotiation process.

The case for restorative justice as it would apply to the disability community and their continued marginalization can be made by examining what the process of restorative justice has to offer all parties involved. There are several examples to examine such as

the use of restorative justice practices as the result of the colonization of Aotearoa and the marginalization of the Maori people, the Canadian government and the First Nations of Canada (Zehr, 2005), or the South African Truth and Reconciliation Commission (Richland& Deer, 2009). Cases of restorative justice used to address wrongs across a large scale, may be a place to start since one of the major complaints about the Americans with Disabilities Act is that, while it is far reaching, it lacks both teeth and enforceability (Consider It, 2018) on a broad scale and many disabled activists would like to see greater enforcement or to change the process of ADA entirely.

On a case by case basis there is a lot the conflict resolution community could offer the disability community if we familiarized ourselves with and practiced structured negotiation (Feingold, 2016). Much like restorative justice practices the process of structured negotiation is a facilitated process that takes place outside the lengthy and expensive court processes that come under filing ADA suits. Much of what happens in the process of structured negotiation is similar to the mediation and negotiation processes with which many conflict practitioners are already familiar. This process would require that the practitioner be versed in ADA law and options for addressing ADA complaints. A side issue needing to be dealt with on this end is the bad reputation that has come with the filing of ADA lawsuits and the perception that those lawsuits are pursued by greedy parties seeking only money (Cooper, 2016) instead of structural change or accommodation.

Academia. The subject of disability in academics is complicated because there are many layers to it. As with the conflict resolution community the academic community must do serious soul searching in regard to biases about disabilities and the

active role academics plays in perpetuating ableism. Academics perpetuates ableism on students who require accommodations, on faculty with disabilities and in the degree programs we offer on campus.

In 2016 Psychology profession Gail Hornstein wrote an article for Chronicle of Higher Education called "Why I Dread the Accommodations Talk". Hornstein spends the article discussing why these talks make her uncomfortable and the article drips with ableism whether she intends it to or not; this while calling herself a "disability rights ally" She calls the process of accommodations "formulaic and often defensive" (para. 3). As she's discussing the student's needed accommodation, she sets the form aside not really looking at it. She continues through the article to discuss how students with mental health accommodations differ in need than students with physical disabilities, and while she believes students with disabilities have rights to ask for accommodation. She admits she did little to help the student in her class. Hornstein says:

> Compared with physical disabilities, psychiatric conditions are far more variable — both for different people with the same diagnosis and even for the same person at different times or in different contexts. People aren't equally anxious, depressed, dissociated, subject to panic attacks, or even learning disabled all the time, or necessarily in all the same ways. It depends on what they are being asked to do, how prepared they are to do it, and what state of mind they are currently experiencing. We as faculty members need to respond appropriately and help students to learn what's a crisis (and what's not), and to understand when it is reasonable to ask for the course structure to be changed or for expectations to be modified (and when it's best to try to cope on one's own).Those are crucial life

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lessons of adulthood, and we aren't helping students who already have problems

to succeed in their lives after college by treating them in a standardized manner or

by overprotecting them. Determining who actually requires assistance, and in

what form, and discouraging students from defining themselves by what

they can't do can be especially important (para. 10-12).

Her general assumptions about disability are detrimental to student success, what

is more she puts the onus of successful completion of a course on the student. This is in

keeping with medicalized ableism that says it is the disabled person's responsibility to fit

into a predetermined structure. She assumes she knows better than the student what the

student's experience with disability is, all while trying to say the process for

accommodations is unhelpful to the student. The structure of accommodation is that if

that student did not have the form - she would not have been able to approach the

instructor. By all accounts it seems form or no form the instructor feels it is the student's

responsibility to manage disability not hers as the instructor and not the institution of

academia. Accounts like Hornstein's frustrate the intentions of accommodations.

On a professional and personal level Hornstein's response is aggravating. I

recently had a student have a panic attack during an online exam proctored by video

recording. She wrote me after she finished the exam to explain what happened. I

watched the video to see the attack, I could see by her answers where in the exam the

attack occurred. She was not asking for accommodation nor did she have a letter on

file. The failed final exam put her overall score at an 84% for the course. I simply

offered her the opportunity to retest. It was not difficult to provide that, she thanked me

for the offer but did not retake the test. Yes, students have to do their part to succeed in

courses, but there is no reason faculty cannot structure our courses or materials in a way that takes some of the burden off students, especially disabled students.

The same structure that puts disabled students at a disadvantage, also puts disabled faculty members at a disadvantage. Stephen Kuusisto is a blind professor who writes about his experience as a blind man, who also blogs extensively about his experience as a blind academic. His experience has been one of frustration, especially he says in a community that claims the progressive values that are supposed to include his "otherness". When he describes the challenges, he faces to other non-disabled faculty he's met with verbal condolences. When he speaks up about his need for accommodation he is met with silence.

In higher education disability access signs are advertisements to the faculty to ignore the disabled. Silence means that accommodation signs are just there to be ignored. Moreover, as every disabled person involved in higher education knows, if you keep speaking up about inaccessibility, you'll be labeled a malcontent. Pejorative labeling attaches to accessibility signs like lamprey eels to fish. "She can't get accessible materials because she's difficult somehow. We all know that." Inaccessible software; inaccessible PDF documents; inaccessible handouts in meetings; inaccessible video conferencing and presentations; building after building without accessible directories; a bureaucracy without a system for resolving these issues…. these are the daily realities for the blind in higher education almost everywhere. The silence of faculty around the nation about disability is a direct reflection of the privilege most have—not needing

accommodations themselves they're free to overlook the signs on buildings.

They're just signs, not icons (Kuusisto, 2019 7, para.14-18).

Stephen is not alone in his experiences Krizia Puig writes:

This is about the freak out but robotic "I am so sorry, do you want to go to

Counseling and Psych" and the "we offer yoga classes on campus" that follows

every time I disclose any of my disabilities or any of my experiences of trauma.

This is about the power points, the workshops, the institutionalized knowledges

about how to handle a "crisis" or a disagreement that reinforce hurtful stereotypes

and that alienate people of color, queer./trans people, and disabled people–while

they supposedly aim to do the contrary. We are dangerous when is convenient for

pedagogical purposes, but also pictured as fragile and infantilized people when

they need too. We are "lucky" to be here and therefore ignorants without any

professional or academic experience. We need to sit down and stay quiet, while

they feel "sorry" and teach us how to handle our oppression. Only sugar coated

forms of truth tend to be accepted (Puig, 2018, para. 3).

When I became a wheelchair user three years ago, I could manage to kind of teach

on campus. If someone was available to load and unload my wheelchair and open the

door to the classroom I could get in the building. Teaching from the lectern was a

challenge the because the housing for the hardware was incased in a stand-up podium

without room to roll my wheelchair underneath so I could not really reach the keyboard

or the mouse to run notes for lecture. Putting notes on the whiteboard was tricky because

I could only reach so high from a seated position. As a class we waited till everyone

wrote down the information they wanted - then I'd erase the board and we continued to

the next phase of lecture. I tried asking students to be scribes for the lecture, but it was too awkward for them. As an unspoken accommodation I started receiving my teaching duties online.

In some respects, this is a wonderful accommodation, it allows for me to teach from home and handle the ebb and flow of whatever the cerebral palsy has in store for me that day. However, it also leaves me isolated from my campus community because it means I don't interact with them often. I can only go to campus if I can find someone willing and able to unload my wheelchair for the meetings, and I can only attend those if they are in a room big enough to accommodate moving the bulky power wheelchair I use. Why not get a vehicle I can get my wheelchair in and out of autonomously? Those range from $50,000-$70000 and I am an adjunct. As an adjunct I have had to remind my department about my needs several times and have had situations occur where I was forgotten because I'm not on campus. Like Stephen, campus is not built for me, and like Stephen if I speak out people get uncomfortable or cranky - usually both. Like Stephen I identify as disabled and as a member of that community as well as being members of the academic community, we have our own set of goings on to be dealing with to continue to raise the visibility of the disabled community.

Another area that academia needs to work on is degree programs. In North America there are thirty-eight Disability Studies related programs according to the American Sociological Association (2019). This is not a advocation for more disabilities studies programs across the country, although that would be movement in the right direction, this is an encouragement to put the topic of disability in more programs. With

only thirty-eight program on the continent it is hard to say that Disability Studies programs have the corner on teaching disability, but they do, and they should not.

Like any marginalized group there should be representation of the issues related to disability at every level of higher education and it should not be confined to African-American Studies, Women's Studies, or Disability studies where people are voluntarily educating themselves on these issues. One in four people in America has a disability. We should be having units in political sciences courses, we should be having medical students take a course on disability from a disabled perspective as well as a medical perspective, or biology perspective. Academia needs more disabled researchers doing research not just about disability, but about all subjects. There are increasing calls from both in and out of academia to make it happen (Avery; 2019, Kosanic & Zimmerman-Janschitz; 2018, Kosanic, Hansen, Zimmerman-Janschitz, Chouinard; 2018, Tregaskis; 2004).

> The low number/percentage of Academics with disabilities in top class universities and other research institutions is alarming, and we have to ask why this is the case and what are possible solutions to change this situation for the better... Though some laws and policies prohibiting employment discrimination on the basis of disability do exist, they are still very rarely followed or implemented. For example, sentences in job advertisements such as "Disabled applicants with identical experience are preferred" or "Taking Action for Equality" or "Disability Confident Employer." What does this really mean for disabled researchers? There is still misinterpretation of the phrases 'equal opportunity' or 'equal opportunity employer.' The principle of equality, which is

guaranteed and supported by non-discrimination laws, precludes comparable

situations from being treated differently, and different situations from being

treated the same way. Hence, any direct comparison with non-disabled applicants

in the job screening process is a presentation of inequality, discrimination and

unfortunately just creates an illusion of equality. (Kosanic, Hansen, Zimmerman-

Janschitz, Chouinard, 2018, para. 2, 4-5).

Everyone who has written about disability in academia has called out the

supposedly progressive institutions for stagnant attitudes and actions when it comes to

accepting and including disability on campus. One in four Americans has a disability and

yet people with disabilities are under-represented in every facet on American life

especially in faculty on campus which is where there has potential for far-reaching

impact to change perceptions about disability.

Disability community. The disability community does a tremendous about of

living, educating, politicizing, advocating and managing around disability whether it is an

individual person out in the world just living or activists and advocates blocking senators

offices or writing articles, it needs acknowledging that the work of making the world

bearable for people with disabilities falls mostly on them. From Ed Roberts to Anita

Cameron, Alice Wong to Leroy Moore, Senator Tammy Duckworth to Lt. Governor

Cyrus Habib many people keep bringing disability issues to the forefront. It needs to

keep happening until real change occurs. The goal of the community has always been

acceptance and truly equal treatment under the law and by society, those are imperative.

If there is one issue that the disability needs to challenge with its own ranks it is

the hierarchy of disability that has been created both in and out of the disability

community. There needs to be discussion about how acquiring a disability is viewed

differently than congenital disabilities. It has to be okay that some disabled people never

identify as disabled, but there has to be discussion about the perceptions that arise from

that. Is there a way to collectively handle or decide what conditions are worth "curing",

or eliminating, or is all of that too ableist? Disability is an extraordinarily complex

issue. It is time that there is real and swift movement within the community away from

only talking or teaching about the social and medical models of disability, they do not

address the breadth or depth of the disability experience alone nor together. Going

forward the community must keep living on, keep advocating, keep teaching and

preaching, but it must do so fully acknowledging the complexity that is disability.

Chapter 5: Discussion and Conclusions

Fear, Fatigue, and continuing the fight

In April of 2019 I was invited, along with twenty other early career scholars, to a first of its kind seminar on disability in the professoriate. The intent of the seminar was to discuss the challenges facing disabled scholars. Some of the presenters were disabled, most were not, and there was palpable ableism that ran through out the whole experience while simultaneously providing a place for us to share and navigate the many mutual experiences that we lived separately and together.

Upon entering the room, we were told our cell phone cameras needed to be deactivated because no pictures of participants were to be allowed. The organizers of the conference did not want anyone "outed" as disabled on their watch. We were there because we wanted to be seen and heard collectively and individually. When asked for advice from lawyers and other long-term professors how we could change institutional culture toward disabled professors without losing our jobs and benefits we were answered in shrugs.

Asking the financial backers of the seminar why disability was not included as a category of funded diversity research got us reprimanded by the organizers and sneered at by the president of the funding body. We asked how to go about publishing in peer reviewed journals when many make no accommodation for disability in their publishing process, we got no answers there either.

What we did find was that we were not alone in our desires to address the many issues we each face, we are united in wanting to change the face and body of the

professorate, so it looks and feels a little more like ours. We found comradery and fellowship and the motivation to be the change we want to see.

The reason for mentioning the seminar is that it was the embodiment for me of what I watched unfold in real time on social media for others as I tagged, sorted and coded the data I was gathering. There were discernable undertones of fear as people hashtaged, tweeted and posted about how badly they needed the Affordable Care Act. They used tones and words of frustration as they experienced other infantilize and minimalize their desire for independent living. Repeatedly they acknowledged in posts and comments that it is wearisome to have a law that is supposed to protect their rights and to continue to have people circumvent the law as they justify disabled people's exclusion.

When it became clear that social media platforms like Twitter and Facebook engaged in questionable privacy practices and there were public outcries to #deleteFacebook, disabled users came to the defense of the platform (Ryan, 2018), not for their violations of privacy, but as a place disabled users found a sense of community and belonging. Without such platforms many of them would experience renewed isolation that online communities help them combat.

The seminar and the online material gave witness to the conversations in which disabled people expressed resigned resentment and fatigue over the fact they are responsible for educating able-bodied people about lives, capabilities, and medical conditions. There is acknowledgement that while they know it is not their job all the time, if they do not educate people on disability, it is unlikely people are going to educate themselves. Tauriq Moosa (2018) expresses the sentiments precisely:

The oppressed are not lost for words: books, articles, speeches all exist and those with bigoted views are welcome to them and, better, moderates are welcome to direct their bigoted friends to these words. We've spoken them already. We've in fact already done the work. It's time to stop expecting oppressed groups to, with some preternatural calmness and civility, simply smile and calmly discuss a bigot's bigotry, to their face, until it unravels and he reaches Enlightenment (para. 16).

Some advocates of disability rights are people with disabilities whose advocacy has ended because entrenched systematic ableism has cost them their lives. The most recent of those disability advocates to lose their lives to an ableist system was Carrie Ann Lucas.

Carrie Ann Lucas, Stella Young and advocating to death

Carrie Ann Lucas, a disability rights attorney with a rare form of muscular dystrophy, died of sepsis on February 24, 2019. She died because her insurance company refused to pay for the treatment to cure the sepsis (Powell, 2019). Stella Young, a disability rights advocate, journalist and comedienne with Osteogenesis imperfecta, died from a delayed response to an aneurysm. While Lucas and Young are not the only disability advocates to die as they worked to change the world around them, what made their experiences different was that both women were advocates in the time of social media and both were active on social media platforms where they were open about their experiences of living with and advocating for disabilities.

What often started out a post about a typical activity like attending a play turned into a public witnessing of discrimination in action. In one of Carrie Ann's posts (Lucas,

2018) she shared pictures of herself and her children who are also wheelchair users getting ready to attend a theater performance for equity and diversity in Colorado. When they arrived, Carrie Ann was informed that the wheelchair accessible seats she had reserved for herself and her children were no longer available because they had filled the seating area with regular seats for high profile donors. When, as an attorney, she pointed out that the theater's actions were against the law, she was rebuked by the stage manager for causing a scene that was disturbing other theater goers. In an effort to appease her the theater offered her family seats that were blocked where the view was blocked by pillars in the theater. She updated the posts when they returned home with the evening events. They never stayed for the performance. She continued the post by saying she was dismayed, but not all together surprised by people's resistance to their presence especially at an event to promote equity. Stella Young shared similar experiences on Twitter.

These women spend much of their time openly advocating for change in the treatment of people with disabilities. What is troubling about their deaths is that disabled advocates are in the precarious to work for rights and benefits they may never see because the systems they seek to change play an active role jeopardizing their lives. People with disabilities should not have to choose between their health and advocating for their rights, but it happens more often than not and many of the most prominent disabled advocates have paid heavy prices for the advocacy. In writing on Lucas's death Robyn Powell (2019) points out that pioneers in disability activism have died due to health complications. Mike Oliver, the creator of the social model of

disability, recently died of a short illness, so did Anita Silvers, a professor and disability advocate at San Francisco State University.

The struggle that disabled activists have says Powell is how to maintain pride and activism when disabled activists are often surrounded by death.

But each time a disabled friend dies I find myself questioning many things in my life. And one recurring question is this: How I can I maintain my disability pride when I am always surrounded by death? It is not always easy. In fact, at times it can feel insurmountable. While some of my friends have died because of their disabilities, others have died because of broken systems that devalue the lives of disabled people (Powell, 2019, para. 6).

Powell is not the only one addressing the issue of the cost of activism for the disability community. S.E. Smith recently wrote about the societal treatment of disability amplifies the importance of advocacy and the pain that comes when disabled people die that much more acute.

Being disabled does not, in and of itself, necessarily predict a shorter life expectancy, though some specific impairments are associated with shorter lives. The numbers are getting better all the time for people with conditions that are more treatable now than ever before; Stephen Hawking just proved, for example, that it's possible to live far longer than the average two to five years after an ALS diagnosis, while people with cystic fibrosis can live forty years or more, rather than dying in infancy as they did in the 1940s. For every disability that comes with a term limit, there are countless others; what kills us are not the impairments we live with, but the way in which society treats us. We die because we can't

access basic health care, because racial disparities are amplified by disability,

because we are crazy and our brains make war on us and sometimes they win,

because some people view us as easy targets for violence and abuse, because

people sometimes do not listen to us when we say that we are hurting, that we

know our own bodies, that something is very wrong (Smith, 2018, para. 14).

Even as advocates and activist people are unwilling to give space and attention to

the issues being raised by disabled people. As a society we need to educate ourselves and

others on disability. As a professorate we need to make sure our colleagues and students

with disabilities know that they have a right to be in academic places and will be wholly

welcomed there. People should have to wear out their health to earn the rights that ae

already supposed to be accorded to them by law and those who are able to them in the

fight for equity ought to be doing so.

The importance and limits of critical scholarship and Foucault

As a master's student I was introduced for the first time to Foucault's idea of

critical theory. His ideas frustrated me because I did not fully comprehend his messages

on the relationship between power and knowledge and the imbalances they create in

society. I disliked the fact that he was critical without supplying solutions to the

issues he raised. Foucault's ideas were expanded on by Stuart Hall (Griffin, 2009), Hall

maintained that the power structures in America "keep the average person more or less

powerless to do anything but operate in a corporatized, commodified world"

(p.338). Hall placed great significance on Foucault's ideas about who got to say what

and who decided what we were not going to say and concurred with Foucault that those

outside the accepted power dynamics got to say very little. Foucalt's work on mental

illness has meaning for the efforts to bring equity to disability. He pointed out that

> People with power drew arbitrary lines between the normal and the abnormal, and
>
> these distinctions became discursive formations that had real physical effects on
>
> those deemed to belong to each group. Over time, these unquestioned and
>
> seemingly unnatural ways of interpreting the world became ideologies, which
>
> then perpetuated themselves through further discourse. The right to make
>
> meaning can literally be the power to make others crazy (Griffin, 2009, p. 338).

The power to make meaning is the power to make someone crazy, or disabled, or

less than, in some way when compared to those considered normal. As a conflict scholar

and a disabled person, I have experienced a profound change of heart in regard to

Foucault's critical theory. It is exceptionally challenging, not to point out the imbalances

of power and knowledge - no, that should be the duty of every scholar, it is a challenge to

say with certainty how exactly to correct such imbalances. That is the limit in critical

theory, there is no panacea at the ready to address the inequity that discourses around

disability have created. Disabled people are trying to change the discourse when they say

to the world that they are not wheelchair bound, but that the wheelchair is an instrument

of freedom. "I absolutely hate the term wheelchair-bound. Being in my wheelchair is

just that freedom, freedom to move about, be independent, get out and about. Freedom to

be me" (Disability Horizons, 2018, para. 20). It is here that I disagree with Hall, I do

believe that the people do have the power to change discourse and we should be doing so

particularly in the unique capacity we have as scholars and conflict practitioners.

Further Research ideas

The intent of study to explore many of the points made in Foucault's work in particular who was talking about what and what they were saying about disability, but it is by no means exhaustive. It would have benefited from the perspective of additional researchers across multiple disciplines. With one in four Americans considered to be disabled there is a considerable amount of research that could be done around disability in all academic fields and that research needs to have disabled participants and researchers as part of the process. By combining the different aspects of multiple disciplines and looking at disability in light of those differing aspects will continue to add to the understanding around the complexity that encompasses disability. Other research for consideration would be to consider the most effective and equitable was of discussing and teaching about disability in the classroom and the workplace.

Moving Forward

I cannot escape feeling compelled to make suggestions how to challenge the power imbalances faced by people with disabilities. Individually I believe there are steps that can be taken to help bring equity and acceptance to disability. So, I would make the following suggestions.

First, examine individual feelings and beliefs surrounding disability. How do personal feelings and beliefs about disability impact the you negotiate it in your own life? Are the ways you interact with disability based in fact, myth, or opinion? In short perspective check your own degree of ableism. Starting here allows people a degree of self-determination in how to address the prejudices they hold.

Second, if you are in education, examine how disability is dealt with in your classroom. Are your courses and materials accessible to a variety of disabilities without having to make them so because you got a letter from access services? Do you discuss disability in classroom as more than just an add on? It often falls in some sort of phrasing like "consider race, gender, sexual orientation, disability, etc." How is disability framed in those discussions? Bell Hooks (1994) says:

Once we start talking in the classroom about the body and about how we live in our bodies, we're automatically challenging the way power has orchestrated itself in that particular institutionalized space. The person who is most powerful has the privilege of denying their body (p. 137).

What if anything is you doing to support and promote the perspectives of disabled faculty you know? There are many communities on campus in need of allies and disabled faculty are among them. If you are not in the classroom and you work outside of education all together, find out what your company policies vision is in regard to hiring disabled workers. If you have the opportunity to do trainings or profession development presentations take time to teach people in your organization about what the ADA says about employment discrimination and use resources from the National Organization on Disability has to say about the benefits of hiring workers with disabilities.

Third, if you are involved in civic or political organizations find out what their views on disability are. Do they actively seek to support the rights and inclusion of people with disabilities or is that not something that is really on the organizations radar? If it's not helpful to make them aware of disability issues in the community. Also

check to see what civic organizations in your community are specifically dealing with disability issues and see what you can do to help the organization.

Fourth, if you are involved in religious practices examine how those practices treat people with disabilities. Are the houses and rituals of worship accessible to all types of different disabilities? How is disability discussed in your religious practice is it a "blessing", or a result of "sin"? What about the religious texts are they available in multiple formats?

Fifth, speak up. When you witness the use of disability as a slur say something. It does not always have to be in that moment, but it should always be addressed. When you see people with disabilities being ignored or disrespected help create a space to challenge such treatment.

Sixth be mindful. This is a broad suggestion to be sure, but it is important. When you enter a space check accessibility. When you talk think carefully about the words you choose when you discuss disability either casually or formally. If you happen to know someone with a disability and want to engage them about it be honest and respectful, but remember it is not their job to educate you.

Final Thoughts

My first ever residential institute at Nova Southeastern University I sat in a presentation about developing dissertation ideas. One presenter suggested thinking of the ideas as a funnel. Put a whole bunch of ideas in at the top and see what is left when it comes out narrowed down at the bottom. The second suggested we look for the lacuna, the gap, in a particular area of research we could fill. Another presenter reminded us that our scholarship needed to be rigorous and heavy in expertise in our chosen area. Still

another presenter urged using the power of the human experience to drive our research. Admittedly, at the time most of us stared back with glazed eyes and buzzing minds instead being outright inspired by the talk. Reflecting on this guidance has me contemplating the ways in which I managed to incorporate it into my work.

On funneling. When I started building a materials base and research questions in my pre-dissertation phase of my doctorate program none of the ideas that I put in the metaphorical funnel were about disability. They were largely ideas about concepts I was learning in my courses, built around ideas of intractable conflicts and diplomacy, and family relationships, which seemed like a soft option though a safe back up. It was a visit to the physical therapist that altered my course. I was being treated at a military facility. When I arrived for my first appointment the physical therapist looked at me and told me I was in the wrong place. This, she said, was a facility for bodies that needed repair, for bodies that could be repaired. Mine was a body, she said, that was made broken and would remain so, as such there was nothing they could do for me there, but I should seek a referral to a civilian physical therapist to see if they would take me on. That was the first of many experiences from thenceforth that went into the funnel. What came out of the funnel was a combination of experiences that set up the opportunity to query whether my experiences were isolated.

On finding the lacuna. Figuring out whether I filled a gap in the research has yet to become entirely clear to me. I have found that conflict resolution practices and theories do not outright include disability in their musings. I have found that disability studies is pretty sure they have the market on all things disability related despite being driven by mostly white, straight, able-bodies academics. I can say with certainty that

neither the medical model nor the social model of disability have advanced the needs and rights of people with disabilities. The models have not done much to give voice to disability issues, so in that way I have begun to provide a more wholistic picture of disability. More than that though I add my voice, and my scholarship to the other scholarly and activist voices that acknowledge that disability acceptance is nowhere near what it should be.

On Rigor and Expertise. Rigor was implied to be strict academic standards for research with little room for nuance or variation - a cold detached clinical type of research that may not necessary benefit its subjects but definitely uses them. My research was rigorous in the exploration of the experience of disability in America post ADA, and it left room for the nuance and variation that comes with disability. It was never intended to use people as data, but to give them data to use. To start discussions and evoke responses. My views on expertise have expanded over the course of the research. While I still believe that area expertise comes from training, education and experience, I think that a person who lives an experience has a type of expertise that brings a different perspective than a field expert. Someone with arthrogryposis has a very perception of the experience than an able-bodied doctor who is considered an expert in the condition. It is the lived expertise of people that ought to be informing the research surrounding disability instead of the research prescribing to disabled people what type of life they ought to be leading.

On the power of the human experience. One of the most profound parts of this research came from reading historical accounts of the disability experience. Many of the background materials included journal entries, legal notices, research manuscripts and

newspaper articles about disability. The experiences contained in those materials were as illuminating as they were depressing. Illuminating because the human experience of disability has not, in its essence has not changed all that much since the early 1800's. Depressing because the human experience of disability has not changed all that much since the early 1800's. Reading historical accounts turned into reading posts and tweets, first-hand accounts in *The New York Times* and still finding much of the same. People with disabilities still want homes, families, citizenship and to be seen as equally human.

   Maya Angelou said, "Do the best you can, until you know better. Then when you know better do better." As a society we have known better than to treat disabled people the way we do. We have known it for a long time. It is time we do better.

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