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**Smart Doctors, Ignorant Language**  
Constructing Bioethical Disability Rhetoric in Medicine

By

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Master of Arts in Bioethics

Laney Graduate School

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Emory University 2018

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An abstract of  
a thesis submitted to the Faculty of the  
Laney Graduate School  
in partial fulfillment of the requirements for the degree of  
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## **Abstract**

### **Smart Doctors, Ignorant Language**

By Sierra Marlo Weiss

Language is paramount in the treatment and perception of people with disabilities. The category of “disability” is used to cover a diverse range of experiences, so I have chosen to narrow the scope of this research to the word *retard* and an associated disability, Down syndrome, as a case study. The transition of the word *retard* during the last century from a medical classification to a pejorative signifies the power of a single word to impact how people view those with this disability. Medical terminology has been used to incite discrimination against people with disabilities and, in the worst cases, language has even proven lethal. The eugenics movement during the Holocaust exemplifies how medical education can be utilized to provoke certain perceptions and actions towards people with disabilities. Certain practices that continue today, like selective abortion, are reminiscent of these eugenic programs and often use much of the same language. While disability sensitivity has been introduced to the specialty of genetic counseling, it has not been incorporated into the education for medical professionals across disciplines—all of whom will encounter patients with one or more disabilities. For their patients’ health and wellbeing, medical care providers have an ethical responsibility to address people with disabilities appropriately and treat them as more than a problem that requires fixing. The project will culminate in the creation of an educational guide for medical students and professionals about addressing and discussing disability in medical contexts. This can be generalized and built on in future work to cultivate disability cultural competency in medical education and prevent many of the historical mistakes surrounding the discussion and treatment of patients with disabilities.

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## TABLE OF CONTENTS

<b>Personal Background</b>	1
<b>Justifications and Methods</b>	2
<b>Introduction</b>	4
<b>Chapter 1: A History of the Word <i>Retard</i>, from Patient to Pejorative</b>	10
The Origin Story	10
Medical Introduction	13
Reutilization of Language	18
Spread the Word to End the Word	21
Implementing Lasting Change	24
The Campaign Continues	26
<b>Chapter 2: The Importance of Language in Medicine</b>	30
The Power of Words	30
Philosophy of Rhetoric	37
Disability Bias in Medical Language	43
Lessons From History	50
Modern Eugenics	59
<b>Chapter 3: Implementation of Disability Cultural Competency</b>	70
Down Syndrome Diagnoses, A Case Study	70
Disability Cultural Competency	88
Available Disability Cultural Competency Review	96
<b>Conclusion</b>	105
<b>Bibliography</b>	110
<b>Appendix</b>	127

## Personal Background

To type the word *retard*, *retarded*, or even the abbreviated *tard* as many times as I have while researching and writing this paper has been immensely difficult for me. I always felt uncomfortable with this word, even prior to my immersion into disability scholarship and advocacy. Aside from personal interactions with people who have disabilities themselves and the incredible scholars from whom I have had the opportunity to learn and collaborate during the past decade, my most salient memories related to disability are those when I was faced with the word *retard*. Even while reading this project aloud to myself during the editing process, I found myself whispering or skipping over the word altogether. During my primary schooling, it was not uncommon for my peers to remark *that's so retarded*. While I never said it myself, I never asked them to stop either. I continued this way throughout my schooling, feeling deeply uncomfortable when *retard* was used as a pejorative, but never speaking up. During my first week in a job, a colleague called something *retarded* and, while I had reached a point where I had started asking people to stop using the word, I did not say anything that time. In another job, my boss at the time, who herself has a child with disabilities, referred to us trying and failing to accomplish something as *retarded*. This really caught me off guard, but I did not say anything and I still regret it.

In conducting the research for this paper, I realized how little I knew about the history of the word. There is a fascinating past and lesson in understanding the word *retard*. The transition from being a word to describe slow movement, to use as a medical classification, to a derogatory remark occurred gradually. A single word's capability to evoke so much history, hate, and power is clear throughout the history of the word



*retarded*. It is a beautiful example of the incredible influence that words have and our responsibility to use appropriate and respectful language.

While years could be spent researching the history of all the different words that have been used to describe people with disabilities and their modern manifestations, the word *disability* itself covers too much to make a feasible masters project. In my work, when I need to narrow the scope of research, I often focus on Down syndrome. In part, this choice is one of personal relevance. The first person with a disability with whom I ever interacted had Down syndrome and some of my first professional experiences in the field were spent at the Down Syndrome Clinic at Massachusetts General Hospital. I have found Down syndrome to be a good case study, as it covers all the areas of disability in which I am interested: prenatal diagnoses, selective abortion, cognitive disability, physical appearance of disability, and language. I chose the word *retard* as the center of this project due to its ties to Down syndrome and its universal applicability to the language surrounding disabilities.

### **Justification and Methods**

This project is a culmination of my prior experiences and research at the cross-section of disability studies and bioethics. As an undergraduate student at Emory I was an Interdisciplinary Studies Major focused on the disciplines of Disability Studies and Bioethics. I wrote my undergraduate thesis about the delivery of Down syndrome diagnoses and their effects on parents' decisions to continue or terminate pregnancies. The research project identified how the diagnostic field has progressed and is becoming increasingly less discriminatory of fetuses diagnosed with certain disabilities like Down syndrome. I submitted the thesis comforted by the efforts that have been made to better

educate medical professionals who provide disability diagnoses about the experience of disability beyond the medical context.

In the year prior to my start in the Master of Arts in Bioethics program, a close friend started at Emory's School of Medicine. He shared his experiences in what he called "sensitivity trainings" that were a part of his first-year education. Different themed panels were hosted to present and discuss experiences of patients from diverse cultures and backgrounds. Topics included race, ethnicity, culture, sexual identity, and non-English speakers, among other topics. I asked who was giving the disability lecture, assuming I would know the professor from my studies as an undergraduate and was shocked to learn that it was not a part of the curriculum. I quickly contacted friends at several medical schools across the country and found that they too had similar cultural trainings and none of them included disability. I consulted my mentors and advisers who work on disability in varying aspects of the medical realm, to find that they also were unaware of any comprehensive trainings provided to medical students not intending to specialize in genetic counseling. Beyond educational advancements in regards to Down syndrome, most prominently, and exclusively in training for genetic counselors, minimal disability focused training is available. All evidence suggested that there is a gaping hole in medical education: there is no training for students about working with patients who have disabilities.

To address this issue, this project will utilize a variety of methods to contextualize the need for better medical training on disability rhetoric and cultural competency and work towards the production of a training manual. I have spent much of the last year having conversations with a variety of professionals in both medicine and disability scholarship, and several who are at the crosshairs of the two, to gather perspectives and

materials. I have compiled and read an extensive list of books, journals, newspapers, legislation, and medical resources. These sources have created the framework of this research and helped shape the historical, contemporary, and first-person perspectives that construct this paper. In many ways, this thesis comprehensively reviews a series of literature and scholarship, compiling resources that shape the historical narrative of language associated with disability and setting the foundation for a much-needed training manual. This thesis is a culmination of many years of thinking about and trying to understand disability language. It is a realization of how formative language is to our perception of those with disabilities and the grave impact it can have if used without appropriate consideration and training.

## **Introduction**

The current terminology used to discuss and describe disabilities and those who experience them is fraught with historical baggage that implies the devaluation and discrimination of those with disabilities. The word *disability* itself suggests a lack of ability, using the often negative prefix of “dis.” While there is a plethora of evidence suggesting that disability terminology is problematic, a pertinent instance of such language issues is exemplified in medicine. Medicine most commonly uses what is known as the medical model of disability, suggesting that disability is a “problem of the person” that “require[s] medical care in order to be fixed” (Baker 2017, 122). Many scholars, advocates, and people with disabilities take issue with this sort of perspective on disability. For them, it ignores the societal barriers and biases that need to be a part of the conversation, as well as the real, lived experiences of people with disabilities. The general perspective of the medical model of disability suggest that disabilities are issues

of the person and should be cured or fixed. This proposal is inherently flawed because it imposes unfounded negativity around disability, is dismissive of the positive aspects brought forth by disability as well, and completely ignores the social barriers. To this end, the social model of disability is typically proposed as a more effective model, suggesting that the issue of disability is actually the result of the society which is constructed in such a way that it creates the category of disability from the naturally diverse occurrence of physical and cognitive experiences of human beings.

Language is paramount in shaping perceptions. As indicated by Aristotle's work, rhetoric has a "theoretical element" which he believed could be utilized to persuade (Aristotle 2007, 16). This "theoretical" aspect of rhetoric that Aristotle points to has very real implications evidenced in history and present in modern times as well. In modern society, "the social and political forces that individualize and categorize people according to particular social norms effectively produce subjects as particular kinds of people" (Taylor 2015, 373-4). In the case of people with disabilities, the words used to describe and discuss those with disabilities often connote certain perceptions. Even though people with disabilities, particularly intellectual and development disabilities, have become more actively and visibly situated within society, "popular rhetoric, and political discourses continue to call in question the worth of a life lived with intellectual disability" (Taylor 2015, 372). The language used in medical settings often lends to the perception that a life with a disability is less good than a life without a disability and, further, that certain types of disabilities result in life not worth living. Actions are preceded by words, and the words often used by medical professionals lead to unfavorable actions towards people with disabilities. Medical education currently fails to address the socially constructed disposition—coined cultural competency by Dr.

Rosemarie Garland Thomson in her recent work in the emerging field of disability bioethics, discussed in more detail in chapter 3—which is necessary for providers to appropriately care for patients with disabilities. As has been seen with other identities, the medical profession has come to realize the importance of cultural competency in the patient-physician relationship and it is time for disability to be included in that education as well.

Historical evidence in conjunction with more contemporary research, suggests that the language used by medical care providers is of particular relevance to the perception of people with disabilities within medical settings and beyond. The eugenics movement exemplifies the translational effect of language into action. Early eugenicists were incidentally all statisticians who utilized statistical methods to define normal populations within society and means to identify those who did not fit within the defined mathematical norm. This work, which will be explored in more depth in Chapter 2, emphasized the importance of scientific and mathematical justification for norming societies. The actions discussed in this project were never nonchalant, but were carefully calculated and validated using sophisticated methodology. During the Holocaust, the Nazi Party implemented new ethical standards and educational measures in medical schools across Nazi occupied territories. To achieve successful outcomes, the regime “needed the willing collaboration of the civil service as well as the participation of the professional classes” and recruited physicians and other professionals to validate the implementation of their goals (Friedlander 1995, 23). New ethical standards were designed to alter the way disability was perceived in medicine, from a population of vulnerable to a population of useless eaters. They gave new directives to medical students about their responsibilities to the state, and who would be deemed a disease

onto the state: people with disabilities first and, later, the Jews and Sinti Roma (Bruns and Chelouche 2017, 592). For the job of killing, which was seen as a role of medical necessity, the Nazis sought physicians who were “young, aggressive, and ambitious” and were eager to prove their loyalty to the party (Friedlander 1995, 216).

Similar considerations of the impact of language on the treatment of people with disabilities is important today as well, particularly as it relates to genetic counseling and prenatal or postnatal diagnoses of disability. Per the evidence from historical treatment of people with disabilities by medical professionals, new ethical guidelines have been instated to protect the rights and autonomy of vulnerable patient populations. Though there are significant contrasts between eugenics practices of the last century and modern genetic counseling, “the focus on mental retardation persists, constituting an icon in which both the history of the field and the cultural meaning of ‘bad’ heredity are condensed” (Rapp 2000, 55). At the epicenter of the concerns about the ethics of genetic counseling, prenatal diagnoses, and selective abortion, Down syndrome is a focal point of these conversations. The providers of diagnoses are tasked with providing neutral yet informative details about a given diagnosis; however, evidence suggests that “when disabilities are involved, both trained genetic counselors and others who deliver genetic information do not always live up to that commitment” (Parens and Asch 2003, 40). How medical professionals present a diagnosis that indicates a future of disability can greatly affect parents’ decisions to continue or terminate a pregnancy. Whether or not the person delivering such information actually thinks less of people with disabilities, this notion is often imbedded in the language used to deliver a diagnosis. Research suggests that the bias in language manifests in patients with disabilities through experiencing poorer quality of health due to “ignorance of health needs associated with

particular disabilities, and the inadequate provision of social and professional support mechanisms for people with intellectual disabilities and their families” (Keywood and Flynn 2019). While the issue of language and disability cultural competency has become particularly relevant as it pertains to diagnoses of disability, it has yet to be assimilated into medical care despite preliminary research suggesting that it affects health care outcomes.

It is vital that medical professionals take on the responsibility of using their words carefully and ensure that they provide the best and most ethical care to their patients. Although their education provides a diverse array of cultural competencies, it rarely includes disability. This is problematic because people with disabilities make up one of the largest minorities in the United States and those with disabilities often face additional medical needs. During their careers, medical professionals more than likely will have at least one patient, if not many, who has one or more disabilities. It is of utmost importance that they know how to appropriately address those patients, in addition to treating their medical needs. Medical professionals have an obligation to their patients to provide an agreed-upon standard of care, in the best interest of the patient. While it is inevitable for biases to present themselves in medical care, it is the responsibility of providers to acknowledge and address their personal biases and mitigate their impact on patient care. Providers are in a unique position of influence and must be especially careful of the language they choose, lest they test the integrity of their oath to serve their patients’ needs. While the gravity of these rhetorical misdemeanors in prenatal diagnoses is the most obvious locus for conversations of cultural competency, this issue must also be discussed across all medical concentrations.

The category of “disability” covers a wide and diverse range of experiences, so it is necessary to narrow the scope of this research. For the purposes of this project, it will focus on the word *retard* and an associated disability, Down syndrome, as a case study. The word *retard* has transitioned in the last century from a medical classification to a pejorative and, as such, signifies the power that a single word holds over the way people view those with this particular disability. The research will explore the transition of the word *retard* and the way it impacted perceptions, both in medical and social spaces, of those with Down syndrome and other disabilities included in the larger category of *mental retardation*. This case thus includes many aspects of disability central to this project’s larger concerns about how disabilities are discussed in medical education and practice generally. As a whole, this project will utilize a very narrow and specific case study to initiate a larger conversation about how language is taught and the weight it should be given where disability and medicine intersect. This project will offer preliminary answers to the proposed questions and initiate a wider conversation that can be continued in future endeavors.



## CHAPTER 1

### A History of the Word *Retard*, from Patient to Pejorative

*I was still mourning the loss of the word ‘retarded.’ I don’t remember ever using the word as a pejorative in my life, but I know I must have, because years after I stopped [...] I would still find it on the tip of my tongue, feel myself craving it like a cigarette. ‘Retarded’ is rich, satisfying in its cruelty. It’s a word that gets its point across [...] Sometimes there’s no good substitute—and yet it’s gone. (Silverman 2016, 176)*

#### The Origin Story

People with disabilities, whether or not there was agreed upon language to describe their conditions, have always existed in some shape or form. Today, every person is likely to become disabled at some point during their lifetime. It is even more likely than ever before for casual interactions with people with disabilities to occur, as they are much more integrated into public social spaces. Historically in the United States, people with disabilities, if they survived birth, were often left to die or were hidden away from public view in institutions or back bedrooms of family homes (Trent 1995, 2). Today, people with disabilities are much more integrated into society. Legislation like the Americans with Disabilities Act, signed in 1990, ensures the equal access and rights of individuals with defined disabilities. People identified as having one or more disabilities by the Americans with Disabilities Act’s definition, make up nearly twenty percent of the U.S. population (US 2018). While it certainly seems like the number of people with disabilities has increased steadily in the past few decades, better medical attention and treatment and more distinct classifications of disability have fueled the accountable population “growth.” Classifying disabilities, however, has been a practice that long precedes census bureau data and the current terminology used to describe it.

In 1805, Benjamin Rush, a Founding Father of the United States, civic leader in Philadelphia, physician, politician, and social reformer, was one of the first to pursue a better understanding of mental disorders (“Benjamin Rush” 2014). His publication, *Medical Inquiries and Observations upon the Diseases of the Mind*, is credited as one of the first modern works to document and classify varying mental illnesses, describing both diseases and symptoms (Rush 1805). By better articulating and defining these so-called “illnesses,” concise vocabulary could be used to better identify disabilities. In this language, “people whose bodies [did] not fit these cultural standards [were] positioned outside of the realm of normal, legitimate, virtuous” (Anderson 2015, 256). While these variations within populations had always existed, linguistic constraints indicating classifications and patterns of mental “illnesses” and “diseases” created a system that allowed for more systematic exclusion and discrimination of outsiders, namely people with disabilities. Rush’s classification into a taxonomy of disabilities solidified disability language, but he also took his work a step further through evaluation, creating the initial exemplification of a disability hierarchy. From its inception, disability language medicalized mental and physical conditions considered abnormal and ordered them into an arbitrary hierarchy based on medical and moral perspectives. It was this second layer to the linguistic definition, the valuing of different disabilities against each other and against the defined normal that became malicious.

The earliest known use of the word *retard* was many centuries ago and appeared in different forms progressively. Use of the word as a verb can be traced to the 15<sup>th</sup> century when it was “always used to describe a blockage, holding back, or slowing” (Peters 2017). According to the Oxford English Dictionary, the word was either from the French word *retarder* or the Latin word *retardare*, from “re- ‘back’ + tardus ‘slow’”

(“Definition of Retard by Oxford Dictionary” n.d.) Another definition of its use as a verb in its earliest form includes “to delay or impede the development or progress of: to slow up especially by preventing or hindering advance or accomplishment” (“Definition of retard | Dictionary.com” n.d.). The word itself originates from the Latin *retardāre*, which means “to delay, protract, equivalent,” coming from the word *tardāre*, meaning, “to loiter, be slow, derivative of *tardus* or slow” (“Definition of retard | Dictionary.com” n.d.). As an adjective, *retarded* appeared in print in the 1600s (Peters 2017) and was first documented as a noun in the form of *retard* in 1668, defined as “a holding back or slowing down” (“Definition of RETARD” n.d.). Around the same time, it also made appearances in religious texts in 1636, “he to his long retarded Wrath give wings” and in another text in 1674, “when it hath passed ye vertex ye motion changeth its nature, & turneth from an equably accelerated into an equably retarded motion” (Silverman, 2016, 178). In its original use, iterations of *retard* were harmless and true to their etymology, indicating slow movement.

As with many words<sup>1</sup> and language over time, the word *retard* evolved and was eventually applied to those with certain intellectual disabilities that were characterized by slower development relative to what was considered normal by medical standards. While this move was innocent in its inclination to better define an emerging classification of cognitive and developmental disabilities, it was also an early example of the challenge of appropriately and respectfully labeling disabilities. Far too often “language may victimize an individual by over focusing on weakness and vulnerability; this affects how the person with a disability is perceived” (Andrews 2020, 76). It has

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<sup>1</sup> Words like gay, fag, butch, dyke, queer, the n-word, bitch, cripple, and several others have gone through similar transitions. Often used to identify a minority or outsiders and then turning into a derogatory slur. Several have since been reclaimed by those who the words are used to describe.

been noted in many studies on the way disabilities are described that the language is inherently negative and indicates that people with disabilities are lesser than the defined norm (Fine & Asch, 1988a). Lennard Davis, a scholar and professor of Disability Studies and the child of deaf parents, suggests in his book, *Enforcing Normalcy*, that “most constructions of disability assume that the person with disabilities is in some sense damaged while the observer is undamaged” (Davis 1995, 14). In a similar vein, while *retard* was chosen as a concise way of describing the symptoms of certain disabilities, it was quickly reclaimed as a harsh slur thrown around with little thought but immense weight, as will be discussed further throughout this chapter. As the evolution of the understanding of the word *retard* shows, it is “a construction whose changing meaning is shaped both by individuals who initiate and administer policies, programs, and practices, and by the social context to which these individuals are responding” (Trent 1995, 2). As with many pejorative terms, the word *retard* was defined by those using it, not by the people to whom it was applied, allowing those who used it to shape public perception of people with disabilities according to their use of the word.

### **Medical Introduction**

The first appearance of *retarded* in a medical setting continued the word’s historical use to describe something that was slow. While describing a labor and delivery in 1785, the process was noted as “retarded labour” (Silverman 2016, 178). This terminology continued the use of *retard* purely as a descriptive word, unattached to any particular classification of persons. It was not for another century until *retarded* was recorded as a description of someone with developmental delays (“History of Stigmatizing Names for Intellectual Disabilities Continued” n.d.). The reutilization of

the word was intended to replace terms that had been developed to define the lower end of the hierarchy of intellectual ability—like *idiot*, *moron*, and *imbecile*—and were measured by IQ levels (“History of Stigmatizing Names for Intellectual Disabilities Continued” n.d.). The introduction of a numerical means of measuring intelligence allowed for evaluation of groups deemed problematic and applied authoritative judgement on them that validated previous negative judgement. The definition in this capacity was to indicate someone who was “slow or limited in intellectual or emotional development: characterized by intellectual disability” (“Definition of RETARDED” n.d.). In 1895, the word *retarded* was first recorded to describe people with developmental disabilities. As has been noted, “*mental retardation* actually meant to supplant *imbecile*, *moron*, and *idiot*—in a good way” (Silverman 2016, 180). Some even think that the terminology itself is quite accurate in describing the disabilities it classifies and is “a better descriptor than “disabled,” which implies someone will never be able to do something, as opposed to being slow to learn it” (Hodges 2019).

It was not until the beginning of the twentieth century that the IQ test was developed by Alfred Binet and Theodore Simon and allowed for a more measured and systematic means of diagnosing cognitive disabilities. When psychologist H.H. Goddard brought the system to the United States (L. Carlson 2015, 144), it took off in popularity and instigated a “whole new toolbox full of terminology” (Silverman 2016, 178). This form of cognitive testing exposed otherwise invisible disabilities, crucially changing the categorization of mental disability. Therefore, the IQ test’s “importance to the history of mental retardation cannot be overstated” (L. Carlson 2015, 144). The ability to scale cognitive abilities in a measured and organized fashion “prompted further steps to be taken in treating the problem,” such as “institutional segregation and sterilization” (L.

Carlson 2015, 145). In promoting a shift from state responsibility to institutional take over, the government “constructed not only institutions but also meaning, defining the public’s understanding” of those who were expected to be institutionalized (Trent 1995, 39). Suggesting that certain people in the population were better off in jail-like settings, being socially and medically monitored and removed from public view and concern, indicated to the public a very specific and unflattering implication of what it meant to have disabilities and where people with disabilities’ place was in society.

Goddard himself considered those with undocumented cognitive disabilities to be “loathsome” and was concerned over the burden such people would put on their families and the greater society. He was particularly concerned about those with cognitive disabilities reproducing and adding to the population of people with mental disabilities (Goddard 1939, 101-2). The IQ test made it possible to detect those who had lower level cognitions but could pass under the radar prior to the implementation of this form of testing and organizing. This refocused the conversation from those who were considered to have lower mental cognition to those who had a high enough IQ to pass the threshold of “mental[ly] deficient” and could seemingly still be sociable enough to reproduce (L. Carlson 2015, 145). This sub-classification of those considered *mentally retarded* was known briefly as the *moron*—a word that has also developed into a pejorative, though less known as a reference to disability.<sup>2</sup> The word *moron* was introduced in an effort to shift the rhetoric from those with disabilities being a “social *burden*” to a “social *menace*,” making those with disabilities sound dangerous and more frightening than just a waste of resources (Trent 1995, 163). The shift towards institutionalization of

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<sup>2</sup> In the extensive research done for this project and searching other terminology, it became apparent how well known it is that the word *retard* is a problematic word. However, other words like *moron* and *idiot* were only indicated as problematic in limited disability scholarship or blogs by people with disabilities.

those considered *retarded* made the classification of *moron* particularly concerning. The worry was that *morons* could camouflage themselves among those deemed suitable for reproduction and procreate despite efforts to mitigate the growth of this particular population. The issue being that the *moron* was “out there among us, and they were doing bad things,” and, as such, “were becoming more and more of a drain on society because of their propensity toward social vice” (Trent 1995, 165).

In a 2013 speech, Tim Shriver, Chairman of the Special Olympics and the son of Eunice Kennedy Shriver who founded the Special Olympics, noted that “the words we use in common language—imbecile, idiot, retard—these are medical terms developed around the turn of the last century to classify people with intellectual differences according to their IQ” (Silverman 2016, 178). The medical community quickly adopted these words and replaced the terminology which was considered antiquated at that point. They started appearing in medical journals, educational materials, and was integrated into the common medical rhetoric of disability diagnoses. A pediatric journal entry in 1909 described those newly defined as *retards* saying, “then there are the ‘backwards,’ or the retards for their years, and those subnormally endowed in respect to mental gifts . . .” (Peters, 2017). The first *Diagnostic and Statistical Manual of Mental Disorders* (DSM) published in 1952 by the American Psychiatric Association included 60 disorders, including “three broad classes of psychopathology,” organic brain syndromes, functional disorders, and mental deficiency. The latter was intended to be synonymous with *mental retardation* and was more clearly demarcated in the *DSM II* published in 1968, which increased its disorder count significantly, including *mental retardation* in a count of 14 listed psychiatric disorders (“History of DSM” n.d.).

The terminology of *mental retardation* was further broken down to indicate the level of care and the opportunity for productivity of an individual with the diagnosis. The diagnosis was detailed in more specific categories of educatable, trainable, and custodial (Beirne-Smith, Patton, and Kim 2006). These categories “reflected societal attitudes favoring services for individuals with intellectual disabilities, regardless of the severity of their disability” (Johanson-Sebera and Wilkins n.d.). The cross disciplinary acceptance of this new terminology brought forth an air of communal investment in those with disabilities and initiated a wave of support groups for families and even advocacy for those with disabilities. This clear and concise language to describe the disability at hand led to “acceptance and empathy” beginning “to replace society’s previous feelings of fear and disdain” towards those with less explicitly explained and categorized abnormalities. This created a greater sense of community within social and familial setting at the time for those experiencing disability in their families and “parents of individuals with disabilities became advocates for their children and began to organize” (Johanson-Sebera and Wilkins n.d.).

While the terminology of *retardation* grew in popularity and became commonly accepted as the most respectful means to describe those with cognitive and intellectual disabilities, public organizations advocating for those with disabilities began to rename their organizations. In 1987, the organization previously known as the Association of Medical Officers of American Institutions for Idiotic and Feeble-Minded Persons “went with a progressive, respectful new term” and renamed themselves the American Association on Mental Retardation (Hodges 2019). Looking back on the language choices in recent history, Peter Sokolwski, the editor-at large for the Merriam-Webster Dictionary, noted that is “surprising to people today that words like moron once had a



scientific meaning” (Peters 2017). At the time when the language changed from that of *moron* to *retard*, there was a feeling that the word and classification *retard* had more scientific grounding and, therefore, was the most appropriate terminology. It was relevant to the organizations advocating for those with disabilities to follow the lead of the medical terminology used to diagnose those with disabilities, to provide the most fluid transition from diagnosis in the hospital to support and care once discharged.

### **Reutilization of Language**

Though the intentionality of the choice *retard* as the new and improved terminology to diagnose and indicate certain disabilities, it was adopted in lay language as a pejorative. While *idiot* and *moron* went through a similar transition, they are frequently used in modern American language without consideration of the historical context of their origin, as most do not know that they originated as medical classifications for disability. *Retard*, however, is a decidedly unacceptable term that is presently associated with cognitive disability. However, within medical spheres, “*mental retardation* remained an acceptable medical term until very recently” and is still “routinely used” to describe medical conditions associated with certain disabilities, like Down syndrome (Silverman 2016, 178). Despite being a “perfectly acceptable word” to describe those with disabilities, in the second half of the 20<sup>th</sup> century, the word *retard* outside of medical settings transitioned into “an insult—one used not simply to slander those actually diagnosed with the applicable condition, but to insult any person or thing.” This sort of use of the word *retard* is problematic because “it is predicated on the idea that it’s undesirable to be mentally retarded” (Hodges 2019). Those with disabilities were already viewed in a generally negative way and the vocabulary provided by the

word *retard* made it accessible to detract the value of something or someone by suggesting that they were *retarded*. The pejorative use of the word *retard* in a negative and condescending manner was a reflection of the perception of disability. Further, the use of the word in this way is problematic because it devalues the lives of people with disabilities and indicates that it should be insulting or even hurtful to be considered disabled.

As the use of the casual use of the word *retard* became normalized during the middle of the 20<sup>th</sup> century, it made appearances in literature and popular culture. In his 1954 *The Courts of Memory*, Frank Rooney wrote, “God, you’re simple, Dick. . . You’ve got an I.Q. about equal to a squirrel’s. You’re retarded, do you hear me?” Here, a clear, casual use of the word *retard* outside the medical context but in direct reference to it, exemplifies the term’s transition to a pejorative (Peters 2017). It was made abundantly clear that having a lower IQ was less valuable or appealing than having a high one, and then, there was a medical term to indicate such a downfall. Suddenly, if someone was making a poor decision or acting in a way deemed stupid, then they were a *retard*, or their actions were *retarded*. While this became insulting to the recipients of this word in pejorative use, it also widely affected perceptions of those who were medically classified as *retarded*. It more explicitly showed the discriminatory notion that those with disabilities were undesirable and had little value in society beyond the punchline of an ill meaning joke.

Use of the word *retard* as a pejorative created issues for new parent and families. Advocacy groups worked together to navigate use of this new terminology while the government agencies quickly changed their institutional names to match proper medical language. Further, as those who were classified as *retarded* themselves were becoming

more present in society, they too started advocating for themselves. In a movement now known as self-advocacy, those who had the sorts of disabilities defined by *retardation* started to “express their loathing for the word ‘retarded’” (Barry 2016). While this was not the first time descriptive terminology for people with disabilities transitioned to derogatory use, this transition occurred during a period in which families were no longer hiding their children with disabilities and those with disabilities themselves were finding their own voices in advocacy. Change needed to occur, however, “the problem with simply abandoning an official label to the insulting masses is that it requires finding a new label.” With a new label comes the acute awareness within the disability field, that these new words will often become an insult over time as well. Then, “yet another new term will be required, and another round of name changing and manual editing will occur” (Hodges 2019). Further, changing the language used to describe disability does not erase the history of previous words, for “behind these awkward new phrases, however, the gaze we turn on those we label mentally retarded continues to be informed by the long history of condescension, suspicion, and exclusion. That history is unavoidably manifest in the words we now find offensive” (Trent 1995, 5).

The length of time during which the word *retard* was used is particularly interesting. It has contributed to the dramatized and enduring fight to end its use, both medically and socially. The language columnist for The Wall Street Journal, Ben Zimmer, noted that other terminologies previously used to describe disabilities that were adopted into lay language like *moron* and *idiot*, “quickly fell out of scholarly fashion as they got taken up in popular usage as synonyms for ‘fool.’” In contrast, the word *retard* was used for a much lengthier period before advocacy groups began protesting its use. Zimmer suggests that the longer use of the word *retard* existing

simultaneously as medical terminology and pejorative led to its perception as “more obviously offensive” (Peters 2017). Continued medical use of the term validated the word and those with the diagnosis with a sense of medical accuracy. As such, the authority provided to the word *retard* in medical settings then provided it with a similar legitimacy in its social use, which made it all the more insulting because it was professionally validated. When the time came to officially push for the change in terminology, it was not a quiet turnover. The movement to change and remove the use of the word *retard* from the vocabulary associated with disability became a full-fledged fight in the social sphere that continues to this day and eventually leaked into the medical realm as well.

### **Spread the Word to End the Word**

Transitioning the word *retard* out of the various locations in which it was used took significant time and effort. The now Chief Executive of The Arc, “the largest national community-based organization advocating for and with people with intellectual and developmental disabilities” (“About The Arc of the United States” 2019), Peter Berns, reflected on the name change the organization undertook in the 1990s. He remarked that advocacy groups’ frustrations with the word *retard* organizations’ names that provided services and support to those with disabilities was “loud and clear.” Berns reflected, “the word was offensive and they didn’t like the fact that it was part of our name, so we changed our name in 1992” (Barry 2016). Initially, The Arc was an acronym for the Association for Retarded Citizens of the United States, but rather than conduct a full rebranding, they “wisely made ‘The Arc’ it’s official name, sans acronym.” In doing so, they also assured that they would not require any future renaming of the

organization should terminology for those with disabilities experience any further changes (Hodges 2019).

While The Arc was one of the first organizations to publicly rename themselves and remove the increasingly offensive terminology of *retard* from their official title, it took twenty years for “popular culture to drag ‘mentally retarded’ through the mud” before others started following suit (Hodges 2019). Many resisted the change knowing full well that it would not be long before whatever new terminology was adopted into their organizations’ names would need to undergo further rebranding. The president of the American Association on Mental Retardation (AAMR) said, “whatever term his organization comes up with” for rebranding, it will quickly be picked up as a pejorative in the same way the word *retard* has. He understands “the AAMR will almost certainly be going through an identity crisis again in 20 years, just to stay ahead of the game” (Cook 2001). Nonetheless, in 2007, shortly after he became the president of the organization, it was renamed the American Association on Intellectual and Development Disabilities (Hodges 2019). Abundant focus on the word *retard* is problematic because “it has kept our gaze on the person labeled mentally retarded. In so doing, research questions and policy formulations have always placed the burden of change on the retarded person” (Trent 1995, 274). As different organizations transitioned away from using the word *retard* in their names, they also shifted their work to reflect the evolving placement of the burden of disability from people with disabilities to society.

During the 2009 Special Olympics Global Youth Activation Summit, the Spread the Word to End the Word Campaign was launched to “raise awareness of the hurtful effects of the word ‘retard(ed)’ and encourage people to pledge to stop using it” (“Spread

the Word to End the Word Pledge” 2020). When the campaign was started, the Special Olympics had just marked its 50-year anniversary.

The motivation for the campaign was driven by a united passion to promote the positive contributions people with intellectual disabilities make to communities around the world combined with a simple call to action – a pledge to stop using a word – that also symbolizes positive attitude change and a commitment to make the world a more accepting place for all people. (“Frequently Asked Questions about the R-Word” 2019)

After 50 years advocating for people with disabilities as active and important members of society, the Special Olympics took upon themselves the fight to end use of the word that had been weighed down by excessive misuse and turned into an insult and a tool for devaluation. The timing of the campaign’s launch was particularly important as then Vice President Joe Biden was present for the games, cheering on athletes and handing out medals to event winners. He made clear during his time at the events that the current administration was committed to addressing the needs of those with disabilities, saying “this is a civil rights movement [...] there’s a need to have changes in policy” (Associated Press 2009).

Though Vice President Biden and the Obama Administration were explicit in their support of the disability rights movement, it was not until a mishap in their own administrative staff that things really began to change. Shortly after the Vice President’s appearance at the Special Olympics, White House Chief of Staff Rahm Emanuel was reported to have called certain liberal groups *retards* (Wallsten 2010). Though the push from disability advocates had been after the removal of this word for a considerable amount of time, this incident “reignited a nationwide debate.” Some, like former Governor of Alaska, Sarah Palin, who has a son with Down syndrome, called for his resignation (Dwyer 2010). The drama of this specific incident culminated in Emanuel

apologizing publicly to Shriver and taking the pledge of the Spread the Word to End the Word Campaign to never use the word *retard* again. While this one event may seem insignificant in the grand scheme of a long-term campaign, it ignited a new flame in the campaign efforts that eventually proved monumental.

### **Implementing Lasting Change**

On November 17, 2009, shortly before Emanuel's insensitive and public use of the word *retard*, Maryland Democratic Senator Barbara Mikulski submitted Rosa's Law. Rosa's Law was put forth to "change references in Federal law to mental retardation to references to an intellectual disability, and to change references to a mentally retarded individual to references to an individual with an intellectual disability" (Mikulski 2010). The bill was inspired by the experience of Rosa Marcellino, a young girl with Down syndrome, who was labeled as *mentally retarded* in the paperwork for her enrollment to elementary school. Her family was struck by the use of the word *retard*, being "a term neither her mother nor Rosa's three siblings felt was effective — much less appropriate — in describing Rosa" (Aerts 2010). Though the officials in their home state of Maryland helped them expunge the language from the health and education codes, Senator Mikulski saw this as an opportunity to incite change nationally. As will be discussed further in Chapter 2, language can garner immense power and authority. When the law uses derogatory terminology it effectively endorses the language and its associated connotations, even if not intended. Though altering the legal verbiage does not necessarily imply a shift in language systematically across all social and professional arenas nor does it immediately change social attitude, it is an important step forward. Changing the language used in legislature indicates a recognition that the terminology is

no longer appropriate and can instigate change or, at least, not validate further use of derogatory language. When she proposed the bill, Senator Mikulski expressed her embarrassment at the use of the dated terminology in legislation. She said, “we thought we were being advanced when we changed it to ‘mentally retarded.’ Now 40 years later, let’s take another big step and change it to ‘intellectual disability” (Aerts 2010).

Rosa’s Law passed the senate and house votes unanimously and was signed into law by President Barack Obama on October 5, 2010 (Mikulski 2010). In the speech he gave at the bill’s signing, President Obama made the strong statement that “Americans with disabilities are Americans first and foremost” and, as such, are entitled to all the benefits and respect American society has to offer. While he recognized that the United States has come a long way in regards to the inclusion of people with disabilities—the Americans with Disabilities Act having celebrated 20 years since its own signing earlier that year—he said, “many Americans with disabilities are still measured by what folks think they can’t do, instead of what we know they can do” (Obama 2010). In the years to follow, almost all states adopted similar legislation committing to changing any terminology referring to people with disabilities as *mentally retarded* to the more widely accepted *intellectual disability* (Makofsky 2014). President Obama’s speech included many thoughtful remarks, most poignantly, a quote from Rosa’s brother, Nick. Capturing the incredible importance of this bill and the change it would create, Nick 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” (Obama 2010).

Rosa’s Law removed the word *retard* from legislative documentation, but it did not halt nationwide use of the word altogether. However, President Obama signified the power of language, and in 2013, shortly after Rosa’s Law passed, the American



Psychiatric Association (APA) removed the categorization of *mentally retarded* from the fifth Diagnostic and Statistical Manual (DSM-5) (Hodges 2019). The APA said that the noteworthy changes in terminology, “address what the disorder is called, its impact on a person’s functioning, and criteria improvements to encourage more comprehensive patient assessment” (American Psychiatry Association 2013). This was yet another step forward to removing the word *retard* this time from the medical field, where the word originally gained notoriety, and recognized the immense power words have in shaping how we think about who they describe.

### **The Campaign Continues**

These steps in removing the word *retard* from language across disciplinary fields marked a tangible change for the disability rights movement. While advocates and those with disabilities themselves were overwhelmingly proud of the change they had encouraged, some felt that excising the word *retard* altogether was not productive. Christopher Fairman, a professor at Ohio State University’s Law School, recognized the value of the Spread the Word to End the Word campaign and does not wish to “praise” the word *retard*; however, he is uninterested in pledging to not use the word and does not think “we should bury it.” He suggests, rather, that the “words themselves are not the culprit; the meaning we attach to them is, and such meanings change dramatically over time and across communities” (Fairman 2010a). Similarly, Amy Shinabarger, a linguist and lecturer of English at Arizona State University, shared a dislike for the word *retard* being used as a noun, but suggested that the power the word holds is far more problematic than the word itself (Silverman 2016, 182-3).

In 1972, far ahead of his time, Wolf Wolfensberger, a psychologist at the Nebraska Psychiatric Institute and a child survivor of the Holocaust, published *The Principle of Normalization in Human Services*. Wolfensberger was a “champion of new thinking about mental retardation” and argued that “mentally retarded people were deviant not as the result of their own choosing but because their ‘observed quality’ was viewed ‘as negatively value-charged’” (Trent 1995, 262). Wolfensberger’s proposals are reflected throughout the ongoing fight for changing perspectives on people with disabilities. He recognized the implications of the way the language is used and pushed for the perception of the problem of disability to move away from the individual and be placed on society. The word *retard* in particular has been pinpointed as a specific problem within public vocabulary, but also is representative of the greater urgency to change the language used to describe disability. The issues that have arisen with many words previously considered acceptable is not necessarily the words themselves, but the implications they connote and the stigmatization they, often intentionally, cause.

While some think completely removing the word *retard* is not a productive solution—some have even suggested reclaiming the word *retard*—the majority of the disability rights and advocacy movement supports the continued efforts to halt the use of the word. A study conducted to measure the effectiveness of campaigns to deter the use of the word *retard*, “found that it only exacerbated negative attitudes or had no effect on the use of the term” (Lyle & Simpican 2015). Although there is still much work to be done in educating students on the power of their words and teaching them that casual use of *retard* as a pejorative is unacceptable, the changes that have been made federally and medically are landmarks in a long fight to rework the vocabulary. The great challenge of the terminology of *mental retardation* is that it “has never had a

permanent residence in any one field.” As such, “it has been, and continues to be, an object of medical, psychological, pedagogical, moral, humanitarian, and political discourse” (L. Carlson 2015, 148). This has made conversation around proper use of the word *retard* quite challenging since its origination within medicine at the end of the nineteenth century to this very day. During this time, the word *retard* has been used in varying contexts simultaneously and with very different connotation, causing concern over perception and misrepresentation of those the word was initially intended to diagnose in a more appropriate manner.

Over a decade since the Spread the Word to End the Word campaign was first started, the campaign is now refocusing their efforts on all people who have intellectual or developmental disabilities. The goal of the campaign in this new iteration is to motivate people worldwide to “take action for inclusion” (“About Spread the Word” 2019). Though there is still tremendous work to be done, change of the word *retard*’s use over time is an important lesson in the power words have and their ability to affect beliefs and treatment. The lessons of the word *retard* will be discussed throughout the following chapter, including the need for diagnostic language to strip the use of this word in the medical sphere, the need for legal terminology to be replaced, and the need for the general public to be more attentive to the origins and suggestions made by the words they use. As was written in *Inventing the Feeble Mind: A History of Mental Retardation in the United States*,

History cannot predict the future. What it can provide are touchstones—memories and visions of what was and what might have been. The future of mental retardation must move beyond its focus on the intellectually disabled person and begin to look at mental acceleration, at the contractors of mental retardation. (Trent 1995, 277-8)

While a detailed look at the history of the word *retard* will not predict the future evolution of disability language, it provides an important context to disability rhetoric and the power of language. As much of the history suggests, the present focus and further development of proper language must move beyond implying that disability is a problem of the person or a problem that requires a medical solution. Language should help in refocusing the conversation to society-level improvements that will change the way people who have disabilities can interact with public spaces and, therefore, be perceived by the public. The word *retard* is just one example of how language can be used to create specific public beliefs and offers many lessons as we work towards a better and more inclusive future.

## CHAPTER 2

### The Importance of Language in Medicine

*‘When I use a word,’ Humpty Dumpty said in rather a scornful tone, ‘it means just what I choose it to mean—neither more nor less.’*

*‘The question is,’ said Alice, ‘whether you can make words mean so many different things.’*

*‘The question is,’ said Humpty Dumpty, ‘which is to be master—that’s all.’*  
(Carroll 1872, 72)

#### **The Power of Words**

Words cannot cause physical harm, but they have immense power to deem actions acceptable. Often, inappropriate or misused language is brushed off as accidental or meaningless, normalizing insensitive language. In the late 19<sup>th</sup> century, *normal*, *normalcy*, *norm*, *average*, and *abnormal* entered the vernacular and solidified negative connotations of different bodies and minds in modern rhetoric (Davis 1995, 24). The word *normal*, meaning “constituting conforming to, not deviating or differing from, the common type or the standard, regular, usual,” created language to identify who and what was normal, providing a linguistic means to identify and label those considered “other” (Davis 1995, 24). This sort of categorization furthered the desire to label those who did not fit the designated *norm* and provided statistical foundation for it. The development of a statistical *norm* led to linguistic derivatives and, through one root word, sheltered a whole class of people with its meaning, while the rest were left stranded. The increasing use of mathematics in medicine during the 19<sup>th</sup> century was empowered in part by the centralization of health care via more established hospitals and clinics. This enabled medical researches to document cases of *abnormality* more accurately according to their new standards and develop mathematical models, discern distribution curves, and, further, establish the *norm*. Creating the category of *normal*

and its counterpart, *abnormal*, formally identified people who deviated from the average in a negative manner.<sup>3</sup> In doing so, it further solidified the place of people with disabilities within the arbitrarily defined social groups, enforcing the preexisting location of people with disabilities at the bottom of the social ladder.

The creation of the *norm* and the parallel language used to refer to the other-than-normal individuals, marked a change in the linguistic scale of measuring people's place in society. Previously, people looked to gods and demigods, idealistic images, and sculptures of the perfect physical specimen, and aimed for this ideal. An ideal, unlike a norm, suggests a goal to strive for but one that is not fully and completely attainable. A norm, on the other hand, creates a concept of what can be achieved and "implies that the majority of the population must or should somehow be part of the norm" (Davis, 1995, 29). In doing so, it alienated those who did not conform with the defined standard of normalcy in any given society. Further, the creation of the category of normal in and of itself assumes that a disabled body or mind is intrinsically problematic. The real problem, however, "is not the person with disabilities; the problem is the way that normalcy is constructed to create the 'problem' of the disabled person" (Davis 2017). This is where disability scholarship seeks to redefine disability in a model that sees disability much differently than the long used medical model, which views people with disabilities as problems in need of fixing.

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<sup>3</sup> Though this era brought forth an extreme focus on the normal and was displeased with anyone below the statistically measured and defined norms, in certain cases being above average was noted to be attractive. For many physical traits, being above the average (e.g. height, intelligence, strength, etc.) were considered positive extremes. Further, while normalcy was the average by which traits were compared and defined, the real goal was to develop what Davis coins "hyper-normality," where the most ideal form of the norm was sought after and reproduced (Davis 2017, 1-5).

The social model of disability, “positions interpretations of disabling conditions as a product of the social environment and not a flaw on behalf of the individual.” Rather than placing the burden of blame on the person with disabilities for veering from the societally accepted norms, this model recognizes “systemic barriers and negative attitudes toward the disabled community as a main factor in these disabling conditions” (Baker 2017, 122-3). It is the creation of the norm and the construction of a world designed for that norm which creates disability. While “impairment is supposed to be the bodily reality that is cruelly mistreated by a society that disables people who are impaired,” the social model of disability flips this notion and recognizes “what seems more likely...that impairment is itself a product of that cruelty” (Allen 2015, 96). In a comic often cited by former Iowa Senator Tom Harkin in lectures he gives on his involvement with the authorship of the Americans with Disabilities Act, several children including one using a wheelchair wait at the foot of a flight of stairs as a man begins to shovel away snow blocking their way up the stairs. The boy in the wheelchair asks, “could you please shovel the ramp?” to which the man shoveling responds, “all these other kids are waiting to use the stairs, when I get through shoveling them off, then I will shovel the ramp for you.” The punchline of the comic is a great line that exemplifies the social model of disability. The boy in the wheelchair says, “but if you shovel the ramp, we can all get in!” (Giancgreco and Ruelle 2002). This shift in thinking about disability is instrumental in how people with disabilities can be perceived and treated by society.

People with disabilities are not the only ones who suffered from linguistic measures meant to devalue them. It has been documented that the racial slurs and other derogatory language directed towards people of color has “played an instrumental role in the perpetuation of race-based discrimination.” Terminology rooted in racism that

promotes discrimination “offered racist speakers a linguistic resource with which to dehumanize their targets and identify them in ‘sub-human,’ rather than fully human terms” (Croom 2013, 190). This is very similar in effect to the way language has been used to signify the place of people with disabilities in society. It often is a tool, whether intentional or not, to devalue people with disabilities, saying that they are less than those who are considered normal. In reference to Eva Feder Kittay’s work *When Caring is Just and Justice is Caring: Justice and Mental Retardation*, when considering lives worth living, “liberal definitions of personhood rely on beliefs about normal human ability that are grounded in masculinist ideas about capacities—including the capacities for rationality and self-sufficiency—and behavior of the white independent male” (Taylor 2015, 374). Likewise, even when overt expressions of racism are not clear or disability discrimination does not seem to be a problem, derogatory subtexts can still be identified. Disability discrimination is often present “in ableist talk of normalcy, normalization, and humanness.” Further the claims, “that surround disability are dependent upon discourses of ableism for their very legitimation” (Kumari Campbell 2015, 109). Language of deviation from the norm is a necessary element of certain diagnoses, however, the tone it takes on in disability diagnoses is not congruent with the experience of disability outside medical spaces. The creation of the norm, and the subsequent defining of abnormal, construct disability and treats it as a problem *to* society, rather than a problem *of* society. This sort of mentality has allowed for the exclusion of people with disabilities from society and, in extreme cases, attempted eradication—as will be discussed further later in this chapter.

The creation of the other has a long history in the United States, including many different minority groups that have and continue to be the object of discrimination.



Often, such discrimination was deemed legal or even legally enforced, including segregation, laws against same-sex marriage, and the inaccessibility of public buildings. While many of these laws have been changed to seem more legally inclusive, the mentality that promoted their original existence lives on in the stereotypes, perceptions, and treatment of certain minority groups. In many places, segregation not only exists, but is far worse than it was in the 1950s (Patterson 2020). Though ramps are now required for all public buildings, if located at the back of the building, they might make the person using a wheelchair question their acceptance in the space. In an article titled *Differences from Somewhere: The Normativity of Whiteness in Bioethics in the United States*, Catherine Myser addresses academics, asking that they consider their position in relation to the norm and how said position affects their work:

This is important for individual academics—whatever their ethnicity, class, gender, sexual orientation, physical abilities or disabilities, religion, nation, region, language, and/or academic discipline—in relation to their own work, it is particularly important for the majority of ‘the field’ that constructs the dominant, mainstream theories and methods. (Myser 2003, 1)

Myser challenges professional colleagues in a plea applicable across disciplines. She asks them to question which scholars and what norms created a field or method and how that answer plays into the results of the work. This is a salient point in the greater context of the power of words, “since our social identities are in part determined by the way society perceives us, and so the way society comes to interact and continues to interact with us” (Croom 2011, 354). Until positionality is questioned and the constructs of the norm unveiled, progress cannot be made, and social identities will continue in this cyclical manner. People who hold themselves to be of greater value to society set the norms

perpetuating societal hierarchies that continues to allow certain people within the norm while pushing others outside the realm of normalcy altogether.

This concept is further explained by Elizabeth Talerman, a branding expert who shared her insights in an article on *How Everyday Language Harms People with Disabilities*. She explained,

We each attach a unique meaning to what we hear. We internalize language and interpret it based on our own experiences, from the past or the present, from our mood in the moment. Words are first processed in the limbic brain, our emotional center, before meaning is made through our rationalizing frontal cortex. Kick off the wrong emotion and all intended meaning may be lost. (Fries 2019)

As she suggests, in the context of marketing, words become associated with meaning. This gives words great power, if manipulated, to shape perception. The language used to discuss disability is an example of this. For instance, people with learning disabilities often face a misconception that they “suffer from poor intelligence” as a result of the perceptions often associated with the word *disability*. Even if they might communicate or learn outside the socially defined, standard expressions of intelligence, this does not mean they are not intelligent. Unfortunately, “our society still breeds toxicity towards those who are not neurotypical; who don’t think or communicate their thoughts in a way that is perceived to be right” (Dunne 2020). When one does not fit within the confines of normalcy—though there is much diversity within the category of normalcy as well—the spectrum that is disability melts into one conceptualization of what disability is. As such, “particular aspects of people are thus created of which power can take hold,” such as race, gender, disability, and other identifiable differences are used to define the person as a whole. Further, “these forms of knowledge and power constitute what is desirable to

be done with people, how they are to be understood, related to, organized, and so on” (Yates 2015, 68).

Words historically associated with disability like *stupid*, *moron*, and *idiot* are used regularly without recognition of their relation to discrimination and exclusion. Unintentionally, in using these words, the history associated with each word continues to perpetuate discriminatory practices based on IQ (Dunne 2020). Though the editor of the Merriam-Webster dictionary believes that the depth to which modern science has come to understand varying disabilities has affected the language used, he also recognizes that “logic and language don’t always go together” (Peters 2017). While words, like *retard*, were eventually deemed inappropriate and squashed from institutionally approved language, this does not imply that these offensive words are no longer used colloquially or that the intent behind these words have not evolved into new language. Lennard Davis suggests an interesting solution to the exclusive definition of normal. He wrote, “if *normal* is being decommissioned as a discursive organizer, what replaces it? I will argue that in its place the term *diverse* serves as the new normalizing term” (Davis 2013, 1). Davis continues to explain how concepts of normalcy were used to create a “monocultural society” and further alienate anyone who did not live up to the standards of the defined norm. To that end, he suggests that diversity is a “much more democratic concept” and moves towards recognizing that an ideal society is homogenous but includes and accepts all people and their uniqueness. Moving towards vocabulary like Davis suggests, recognizes that human variation is, in fact, normal.

## Philosophy of Rhetoric

Beyond the confines of disability related language, rhetoric has a long history of manipulating perceptions. Philosophical perspectives on the importance of rhetoric has been studied by historical and contemporary philosophers alike. The concept of *rhetoric* goes beyond concepts of etymology. Instead, rhetoric “investigates how language is used to organize and maintain social groups, construct meanings and identities, coordinate behavior, mediate power, produce change, and create knowledge” (“What Is Rhetoric?” n.d.). Aristotle provides a more simplistic definition of rhetoric. He said that “in the most general sense, [rhetoric] can be regarded as a form of mental or emotional energy imparted to a communication to affect a situation in the interest of the speaker” (Aristotle 2007, 7). Rhetoric, as Aristotle describes it, is more about the tone and contexts of how words are spoken rather than the words themselves. This is an important reframing of the power of words as it suggests that the issue is not the words themselves, but the way they are spoken. However, if words are used repeatedly in a certain way with a specific connotation—as has been seen with the word *retard*—it can become associated with that word to a point where the problem of its use and the word itself are inseparable. Aristotle’s work, in particular his book “On Rhetoric,” shaped and continues to have “an enormous influence on the development of the art of rhetoric” (Rapp 2010). Aristotle’s work is necessary for unpacking the importance of universal language, while more contemporary philosophers tackle the explicit implications of disability-related rhetoric.

Though the root of the word rhetoric typically indicates “a speaker, especially a speaker in a public meeting or court of law, sometimes equivalent to what we might call a ‘politician’” (Aristotle 2007, 8), the implications of rhetorical study spread far beyond

the political sphere. Rhetoric, as defined by Aristotle, is the “ability, in each [particular] case, to see the available means of persuasion” (Aristotle 2007, 37). Rhetoric goes beyond the words themselves and considers how they are used to suggest a certain way of perceiving the object of description. It is a powerful form of speaking. Rhetoric can be used to manipulate an audience. And, “since few of the premises from which rhetorical syllogisms are formed are necessarily true,” it gives the speaker great power to manipulate what the audience understands to be true. For, as Aristotle notes, “most of the matters with which judgement and examination are concerned can be other than they are,” so the speaker concocts a truth based on what they believe to be true, rather than what might necessarily be the truth (Aristotle 2007, 42).

In recognizing the power of rhetoric, Aristotle argued that “great harm can be done by unjustly using such power of words,” particularly to “the most useful things, like strength, health, wealth, and military strategy.” Almost foreshadowing the devastating histories that are shown later in this chapter, Aristotle believed that by using a word “unjustly” one can do “the greatest harm” (Aristotle 2007, 36). This is of particular importance for those in positions of power, whose words are likely to be believed more readily. Aristotle notes that the power of rhetoric to persuade an audience goes beyond the words that are said, but also affected by who is saying them. He wrote, “[there is persuasion] through character whenever the speech is spoken in such a way as to make the speaker worthy of credence.” It is more likely that those we consider “fair-minded” be believed at their word than others, based on their validity and position (Aristotle 2007, 38). Further, speakers are considered persuasive for three reasons provided by Aristotle: “practical wisdom [*phronēsis*] and virtue [*aretē*] and good will [*eunoia*].” While a speaker might not have all three of these characteristics for persuasion at the

same time, they are each powerful in their own right and dangerous when not combined appropriately. In such cases “through lack of practical sense they do not form opinions rightly; or through forming opinions rightly they do not say what they think because of a bad character” (Aristotle 2007, 112).

These considerations are of relevance to medical professionals. Medical professionals are in a place of “credence,” patients often defer their decisions to the opinion of their provider. Further, when seeking treatment options, the provider might give unsolicited advice in the very rhetoric used to provide such options. As Aristotle suggests, “the first thing to be examined was naturally that which came first by nature, the facts from which a speech has persuasive effect.” In a position of power, having more access to information and medical understanding than the contextually defined average patient, the medical care provider supposedly presents the facts. However, by tailoring the information presented, the provider can persuade the patient towards whichever course of action the provider deems most fitting. The second consideration for examination is “how to compose this language” because the words used to deliver information in a medical setting can greatly affect how the options are perceived by the audience. And, finally, the “third is something that has greatest force but has not yet been taken in hand, the matter of the delivery” (Aristotle 2007, 194-5). More so than the speaker and the words they use, is the way in which the words are delivered. The way in which this information is delivered is at the discretion of the medical professional and can greatly affect how the information is interpreted by the audience. This leads to the necessary recommendation that medical professionals be considerate of how they present information and the power of their delivery in dictating the patients’ decisions and overall health.

Michel Foucault, a contemporary philosopher, unpacks the relevance of language to modern issues of medicine. Foucault suggests there are three aspects of understanding a person's place in relation to truth.

First, a historical ontology of ourselves in relation to truth through which we constitute ourselves as subjects of knowledge; second, a historical ontology of ourselves as subjects acting on others; third, a historical ontology in relation to ethics through which we constitute ourselves as moral agents. (Foucault 1997, 262)

These three aspects, as Foucault calls them, are important to better understand Aristotle's ethics of rhetoric. For everything said is intrinsically related to that word's history, the speaker's history, and the audience's history. Together, those three components affect the meaning of what is being said. Therefore, it necessitates that the speakers be ethically considerate of their speech in order to avoid negative or inappropriate manipulation of the words or audience.

Much of Foucault's work points to language and truth as opposed to rhetoric; Foucault turns to the words themselves. By understanding and illuminating the formation of words and perceptions, Foucault suggests the immense power the speaker possesses. As Foucault points out, "objects are not waiting, fully formed, and exterior to discourse, for their discovery by the discipline that was destined to know them." Instead, "discourses 'systematically form the objects of which they speak'" (Yates 2015, 67-8). In this view, discourse plays a similar role to Aristotle's rhetoric. Both discourse and rhetoric suggest that an object is primarily based on how it is described. Additionally, Foucault points to the "powerful role [...] allocate[d] to language and symbolism in the construction of disabled identities and disabled people as a population" (Hughes 2015, 81). Further, "Foucault was the first (or the most persuasive) to describe how, through a

supposed knowledge of the ‘normal case,’ differences among people become targets of power” (Allen 2015, 93). Foucault’s claims suggest the power of description in defining an experience and shaping societal perception. Allen’s analysis of Foucault’s work provides a crucial addition, suggesting that power is exercised by those making distinctions between words and associated categories. Once the opportunity categories have been defined, there is then the opportunity for evaluation, which is where the greatest occasion for abuse of power is presented.

That being said, as indicated by one of Foucault’s contemporary scholars, “philosophers have been relatively silent concerning the history and state of mental retardation as a classification” (L. Carlson 2015, 133). While Foucault’s work is not directly related to people with disabilities, his writing is however, applicable to the topic at hand. In addition to the three domains mentioned previously about truth,

Foucault identified three additional domains [...] from which to engage in a critical ontology of ourselves: (1) the domain of truth through which we become constituted as subjects of specific forms of knowledge; (2) the domain of power in which we are constituted as subjects acting upon others and acted upon in particular regulated ways by others; and (3) the domain of ethics ‘through which we constitute ourselves as moral agents.’ (Yates 2015, 67)

As opposed to the first three domains which ask that we place ourselves in the context of history, these additional domains explain our relation to truth and the knowledge circulated by society. In the context of people with disabilities, these three domains are necessary to understand that the perception of people with disabilities is concocted by societal “truths.” Foucault’s scholarship is supportive of the social model of disability, showing that disability is a product of societal conception rather than a problem of the person with disabilities, as the medical model of disability suggest. Further, scholars of his work suggest “that disabled people would benefit equally, if not more, from



arguments that valorize their voices, their embodied experiences, and their collective efforts to establish rights and overcome discrimination” (Hughes 2015, 79). While knowledge and truth are usually created by society and the powerful voices within society, truth should come from those who actually experience what is being described—namely people with disabilities and their close relatives and caretakers.

The truth of disability is complicated to unpack, for people with disabilities have very different experiences of living life with their disability. In some cases even people with similar disabilities might have very different lived experiences. The goal of seeking the truth of the lived lives of those with disabilities is less a search for a universal truth to the experience, but creating an atmosphere of open-mindedness to allow each person to provide their own definition and experience. However, people with certain intellectual or cognitive disabilities may not be able to provide the truth of their own experiences, so caregivers and other close family and personnel may be able to provide approximations of their experiences based on their observations and participation in their lives. Nonetheless, the appropriate space should be made for each individual truth to be defined by the individuals who experience disability. While knowledge is in many ways socially developed, typically constituents of said social space are participants in defining that knowledge. In many ways, people with disabilities have consistently been excluded from participating in making social definitions and have solely been the recipients of exterior definitions. These social definitions have been maintained even as people with disabilities have been increasingly included in society and it is time for them to have the opportunity to define the truth of their own conditions and experiences.

Philosophical perspectives on rhetoric, knowledge, and truth provide a framework for discussing the implications of language. Aristotle suggests that rhetoric

can be used as a means of persuasion, a means for the speaker to assume control. A variety of factors contribute to the persuasive power of rhetoric. The words themselves, the speaker, and the delivery of the speech greatly affect the audience's perception.

Unlike Aristotle, Foucault considers the construction of rhetorical speech. He asks that the experiences and perspectives of the objects of rhetoric be taken into account. His work leads us to consider, for example,

how one's identification as a 'person with learning difficulties' is coextensive with a particular 'way to live,' and how people relate to and interact with all of these factors. The question that must now be addressed then, is this: how are these realizations useful in evaluating care services and proposing changes? (Yates 2015, 69)

By bringing together these different aspects of rhetoric, a more accurate understanding of an object's existence can be unveiled. Some of the works of Aristotle and Foucault plead for bioethical disability rhetoric in medicine, recognizing that the placement of words as well as the words themselves have great power in altering perceptions and influencing decisions.

### **Disability Bias in Medical Language**

Medical professionals are viewed by patients as individuals who possess great understanding (far greater than that of the patient) of the human body and its many facets. This creates a situation where the patient, regardless of whether they have been given autonomy, may defer to expertise of the medical professional. Language plays a key role in this exchange. While words are inherently powerful, the context of speech adds further significance. Words are often tied to a historical etymology, identifying both the construction of the word as well as a connotation about the object of its

depiction. Further intensifying the weight of a word is the context of where it is spoken, who is speaking, and the recipient of the words. Through concepts of normalcy and its antonym, abnormality, disability is defined. The field of medicine has defined the line between normal and abnormal. Returning to Foucault, many scholars of philosophy and disability studies consider that his “exploration of biopower reveals how the medical and statistical sciences produce impairment through the comparison of the body that is judged as healthy and able-bodied with the body that is judged as unhealthy and disabled” (Taylor 2015, 386). It is through these means that “impairments” become disabilities that are contrasted to the “normal” body, causing people with disabilities to be pushed lower on the hierarchical social ladder.

In some cases, words can suggest a lesser value, such as the word *disability*. The word *disability* “is a linchpin in a complex web of social ideals, institutional structures, and government policies,” which indicates in just one word what a person with disabilities is and where that individual should be situated in society (Simi Linton 1998, 10). Language used to describe disability can become problematic in medical discussions because it implies that having a disability is both burdensome and negative. For example, Down syndrome is a well-known and identifiable disability by most in the general public; however, “the content of that recognition varies considerably, and may well stand orthogonally to the conventional scientific description” (Rapp 2000, 89). The presentation of such a diagnosis will differ from counselor to counselor and patient to patient based on the way the information is delivered and who is receiving it. Aside from having concerning histories, the phrasing used to discuss disability can be problematic. Language can be used to “victimize an individual by overfocusing on weakness and vulnerability” (Andrews 2020, 76). Language associated with disability can make

individuals with disabilities seem less valuable, exploiting the so-called weaknesses that are created by disability. Many people who use wheelchairs are comfortable with their state of physical being and often consider their wheelchair to be an extension of their body. However, the common phrase used to refer to them being “confined to a wheelchair” emphasizes a trapped feeling (Fine & Asch 1988a). This sort of phrasing is common in language used to describe disability. Such language implies that the experience of disability is unpleasant and undesirable. In many cases, this juxtaposes the lived experience of those who actually have disabilities.

These juxtapositions, hidden in word choice rather than explicit discriminatory language, connect disability to a medical condition. Some scholars go as far as to suggest that the category of disability “can only be constituted as a ‘real’ population in the wake of medicine’s [plunge] into the marvelous density of perception” (Hughes 2015, 83), suggesting that disability can only be defined beyond the medical scope of understanding. Unlike disability scholarship, which discusses disability in a societal context, medicine consistently posits that disability is a problem in need of treatment or total cure.<sup>4</sup> What is normal, as defined by medical standards, is the healthy body. Anything not within the confines of that definition is a problem that requires immediate attention. But perhaps people with disabilities do not fall into the category of patients who need to be cured. While people with disabilities often experience medical needs that require treatment, they also have bodily differences that should be accepted without

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<sup>4</sup> This sort of language in medicine is particularly present in medical research around disability. Most research is focused on curative measures prenatally or supplements and intensive therapies soon after birth to mitigate or remove the disability and its symptoms. As will be discussed in Chapter 3 in the case study of Down syndrome, language of removal and solution are also very common during disability diagnoses, suggesting that having a child with a disability is problematic and that the solution is to terminate the pregnancy and try again.

negativity, judgement, or fixing. As Aristotle astutely noted, “neither is it the function of medicine to create health but to promote this as much as possible; for it is nevertheless possible to treat well those who cannot recover health” (Aristotle 2007, 36). While people with disabilities might never meet the ideal standard of health, this does not mean that they are not healthy. When possible, the medical needs of people with disabilities should be met. If improved health is not possible, they must be met with respect for their personhood because at the end of the day, they are people first.

Unfortunately, people with disabilities are often seen as just that, their disability. The language used to discuss disability is often stigmatizing, suggesting certain negative connotations. It is the very description of a diagnosis or projection that can play a role in outcomes and perceptions. As research has shown, the intensity of a diagnosis and its projected effects on the life of the person affected attitudes towards abortion rather than the specific disability (Rapp 2000, 129-30). The director of the Beach Center on Disability at the University of Kansas, Michael Whmeyer, pointed out that “it often doesn’t matter what the word is.” There is a long history of evolution in the language used to talk about disabilities. He continued, “it’s that people associate that word with what their perceptions of these people are—as broken, or as defective, or as something else” (Barry 2016). As seen in the case of the word *retard*, the word became a tool to devalue people with disabilities. However, the concept of disability is not inherent to the biological makeup of human beings. Rather, concepts of impairment associated with disability are “artifact[s] *implanted in the body* by the discipline that measures deviation” (Allen 2015, 96), through professional and institutional as well as societal uses of such discriminatory language. For example, the language used to provide prenatal diagnoses of disability like “birth defect’ or physical ‘deformity’—must alert us

that we are very much in a world of opinion, of ideology, rather than a cool, scientific world of facts” (Davis 1995, 163). Though these are older ways of describing disability in prenatal diagnoses, their use has not been discontinued.

The mentality that allowed words like *defect* and *deformity* to be acceptable for so long continues to thrive through evolved terminology. These “actions emanate from an embedded conviction that disability is devastating, or at least disturbing, for both child and family” (Dworetz 2014, 174). While medicine now boasts of patient autonomy, patients are still under societal pressure to act according to the norm. Modern medical developments like prenatal screenings are seen as a means to help parents make fully informed, autonomous decisions. Genetic counseling was first coined in 1947 in an effort to promote “ethical neutrality” as a means to foster “personal choice in the century-old eugenics debate about society’s responsibility to encourage or discourage reproduction in certain individuals and families.” The geneticists who coined the phrase “undoubtedly believed in the moral superiority of the position he was trying to map, older scientific practices assumed that experts should give directive advice in order to promote racial improvement (Rapp 2000, 53). These well intended though problematic reasons for bringing forth genetic counseling continue into the modern paradigm.

Though the goal was to promote personal choice, parents “are not free to escape the burden of choice that the new technology creates.” In putting the choice on parents, it gives parents the flexibility to make decisions that are right for them, removing complete control from the medical professionals. Regardless, “they [cannot] avoid being implicated in the enlarged frame of moral responsibility that accompanies new habits of control” (Sandel 2009, 89). Though the parents are responsible for making the decision, societal and medical constructs affect the way in which the information is delivered. For

example, when a genetic counselor solely provides a list of medical symptoms associated with a disability but fails to address the lived experiences of those with disabilities, they portray the diagnosed disability in a biased manner. This reflects a kind of biological essentialism where humans attempt to simplify human existence down to DNA, suggesting that genes define who we are. While we can certainly learn a lot about the human species from genes, it is important to resist such extreme simplification of the human experience because genes alone do not in themselves define disability. Genes cause human presentation to appear a certain way, but it is the human mind, social atmosphere, and language that defines human existence. While our genes define how we look, it is our cognition and social environments that choose how we react to fellow human beings. A person with disabilities will only have the opportunity to succeed if given the space to fill their own existence rather than be confined to the expectations of those around them. To that end, the medical provider is still ethically responsible for presenting parents with unbiased information.

Contrary to popular belief in medicine, “there is no sharp boundary between ‘normal’ and ‘unhealthy.’” The risk assessed by prenatal screenings and genetic testing has “been arbitrarily defined” according to socially defined norms (Waldschmidt 2015, 201). While much of the available research about bias in medical language discusses disability diagnoses, these arbitrary boundaries of normalcy could conceivably continue to affect patients with disabilities throughout their lives. The Down Syndrome Clinic at Massachusetts General Hospital ensures that their patients are treated with the utmost respect, even when the patients are often not considered capable of making their own decisions. For example, the Clinic has developed a plethora of patient resources to give people with disabilities as much autonomy as possible. The social story *My Facemask: A*

*Coloring Book of Adventures* teaches patients how to properly wear a sleep apnea mask—sleep apnea being a common symptom associated with Down syndrome. Their social stories, a learning tool used to educate through simple narratives and participatory activities, empower patients to be a part of their medical care to the best of their abilities. *Talking to the Doctor* is a social story that helps patients identify and practice ways to express their feelings to their doctor and ask questions about their medical care (Weiss 2015). Social stories provide a means to educate and empower people with disabilities and their families in medical situations. Resources of this nature work to mitigate the negative connotations of disability in medical settings and redirect care to focus on the person and not their disability. In situations where these resources are not present, medical professionals can serve as a mediator in the way a social story is meant to, allowing the opportunity for the patient with disabilities to share their perspectives and concerns and be appropriately responded to. They provide a useful guideline as to how patients can either empower themselves or professionals can learn to better communicate with their patients and adjust to their needs.

The problem of disability bias in medical language is going to take time to resolve. The current status is that the “problem” is often still situated around people who have disabilities. Medicine works tirelessly to treat, cure, and fix patients’ many ailments and impairments, but disability rights activists and scholarship are no longer willing to allow disability to be included on the list of problems requiring fixing. Amy Silverman, a journalist and mother of a daughter with Down syndrome, conducted an exhaustive search of all the words that are negatively associated with disability:

Blind, crazy, cretin, cripple, daft, deaf and dumb, deaf-mute, deformed, derp, differently abled, the disabled, disabled people, dumb, epileptic, feeble-minded, fit, freak, gimp, gimpy, handicapped, hare lip, hysterical, imbecile, incapacitated,



idiot, invalid, lame, lunatic, looney, mad, maniac, mental, mentally deficient, mentally defective, mentally disabled, mentally deranged, mentally ill, midget, Mongol, mongoloid, mongolism, moron, nuts, patient, psycho, psychotic, retarded, schizo, schizoid, schizophrenic, simpleton, slow, spastic, spaz, special, stupid, sperg, sufferer, tard, victim, wacko, wheelchair bound, Yuppi flu, zip.

It is hard to find a word to describe or discuss disability that is not somehow implicated by history. Silverman's solution was to use the word *ridiculous* because she could not "think of anything else to say" (Silverman 2016, 177). It is unlikely that all of the words from her search will be removed or replaced, especially considering the cyclical history of disability classifications transitioning from patient classification to pejorative. What medical professionals can do, however, is become more aware of the insinuations of the words they use and take greater responsibility in working towards a less biased, disability rhetoric that allows for the best treatment of their patients with disabilities. It is time the logic suggesting that disability is the problem or that the medical field is problem, to the limits of medicine being the problem in need of fixing. This presents the opportunity for a solution to be developed by fixing the knowledge gap and improving the approach to disability in medicine. The burden would then be removed from the patient and would be situated on medical professionals to acknowledge that there is an inadequacy. The patients and their medical team would then be positioned to best acknowledge the patient's lived experience and address medicine's current limitations.

### **Lessons from History**

World War II resulted in a variety of ethical conversations. Most notably, the Nuremberg Code was developed in reaction to the atrocities committed during the Holocaust. The Nuremberg Code is the ethical code of conduct for human subject

research that resulted from the Nuremberg Trials, which tried former high-ranking Nazi Officers and medical functionaries, including doctor Karl Brandt (Schmidt 2008). The Codes puts fourth ten guidelines for conducting ethically appropriate research on human subjects and is widely regarded as a landmark transition in ethical accountability in biomedical research. While Brandt's work during World War II is notorious for its lack of ethical grounding and completely inappropriate use of human research subjects, what is often not discussed is the key role, as subjects, people with disabilities played in his ethically fraught experiments ("Nuremberg Code" 2018). There are many accounts of the mistreatment of people with disabilities throughout history, however, their often-forgotten role in the Holocaust in particular exemplifies the immense power of words.

People with disabilities were easy targets for the Nazi Regime to begin experimenting with eugenic practices as they were already mostly separated from society. Further, in the mid 1900s, there was a general sense of embarrassment in having a person with disabilities in the family, so families were quick to send family members with disabilities away to institutions. During this same time period, the eugenics movement was blossoming in Europe and the United States even prior to beginning of World War II. The Nazi Regime was meticulous in their preparation of the German people and the medical professionals who would perform the euthanasia. Rather than demand cooperation or force doctors and nurses to perform such heinous acts, they introduced a new set of ethical standards to medical education. The sterilization of a "conservative" approximation of about 375,000 people with disabilities, "representing about 5 percent of the German population" (Friedlander 1995, 30) and the murder of some 80,000 to 100,000 institutionalized patients and over 5,000

institutionalized children (Lifton 1986, 142) were a matter of seemingly innocuous words transforming into murder.

The Nazis drew on the concepts of eugenics developed at the end of the 19<sup>th</sup> century by the likes of Isaac Galton, Karl Pearson, and Ronald Aylmer Fisher. These early eugenicists all came from the field of statistics, which is noteworthy as “the central insight of statistics is the idea that a population can be normed.” This maxim developed the concept of the norm that deemed people with disabilities abnormal. By creating a statistical norm, averaging the mean of human variation, it also “divid[ed] the total population into standard and nonstandard subpopulations” (Davis 1995, 30). These sorts of mathematical “interpretation[s] of ‘normality’ gave way to the idea of ranking, with those deviating from the norm located on a continuum from higher to lower scores” (Barnes and Mercer 2004, 32). The division created by statistical averaging of human experience led to a separation of the abnormal from the normal and the desire to “norm the nonstandard” (Davis 1995, 30) or increase the position of a person on the continuum of normality. And, if a person could not conceivably be normed, the theory of eugenics suggested that they be removed so as not to taint the normal population. However, “normality is concomitant with ‘deviation,’ which will always be produced so long as people with and without disabilities strive for normality and for a life in the heart of society” (Waldschmidt 2015, 192). Beyond the eugenic push for the removal of those with undesirable traits as defined by a given society, this dichotomy enforces a constant effort by the population as well to seek normalcy. The goals of these statisticians were to remove those considered negative deviation from societal norms. To do so, they suggested that those deemed normal should exclusively be allowed to reproduce, in the hopes that this would cause the decidedly unacceptable traits to fade away.

The United States was one of the first countries to implement eugenics concepts in a systemized fashion. The Eugenics Records Office was established in Spring Harbor, New York at the turn of the 20<sup>th</sup> century. The office oversaw the collection of family histories and information of the surrounding areas and came to the conclusion “that people deemed to be unfit more often came from families that were poor, low in social standing, immigrant, and/or minority.” They claimed that the unattractive traits in these families were based in genetics, rather than the more likely causes, such as poverty, lack of education and other resources. In order to “norm the nonstandard,” sterilization methods were established to ensure that those who possessed undesirable traits would not procreate and produce further generations of undesirable U.S. citizens (“Genetics Generation” 2015). The legal approval for this program was solidified in the 1927 Supreme Court ruling of *Buck v. Bell*, which questioned the sterilization of people in the U.S. The court decided to “pursue sterilization” and justified it as a means for “institutional population control” (Trent 1995, 200). Though the program did not last, in the time of its existence, 33 states created their own sterilization programs and an estimated 65,000 Americans were sterilized (“Genetics Generation” 2015). Interestingly enough, the rulings of *Buck v. Bell* have never been officially overturned. While certain state statutes upheld by the ruling have been repealed and “its reasoning has been undermined by a subsequent Supreme Court decision striking down a law providing for involuntary sterilization of criminal,” it still remains constitutional (“The Right to Self-Determination” 2014).

In 1933, under Nazi control, the German eugenics program took the established methods of eugenics even further. Like the United States, under the Law for the Prevention of Progeny with Hereditary Diseases, Adolf Hitler instated legislation

allowing for the sterilization of “anyone who has a hereditary illness” (Rainer Schulze 2013, 19). Normalizing those deemed unfit would not be sufficient for the Nazi Regime. The only way to rid society of undesirable individuals was to remove them from society altogether. This law “opened the attack upon the handicapped and served as the cornerstone of the regime's eugenic and racial legislation” (Friedlander 1995, 26). Early in Hitler’s political career, he promised the people a purified *Volk*. Additionally, a publication in 1920 by jurist and law professor Karl Binding and doctor and medical professor Alfred Hoche paved the way for a rhetorical shift within the Nazi Party’s public messaging. The publication, titled *The Permission to Destroy Life Unworthy of Life*, began to change the German people’s mindset. The publication described “unworthy life” to include

the incurably ill but large segments of the mentally ill, the feeble-minded, and the retarded and deformed children ... they stressed the therapeutic goal of that concept: destroying life unworthy of life is ‘purely a healing treatment’ and a ‘healing work.’ (Lifton 1986, 46)

The piece proposed an intriguing metaphor, naming the state as a diseased patient in need of purification through medical treatment, requiring the removal of illness via the legal and political system. These publications paved a clear path for Hitler’s forthcoming political goals. It inspired a new mentality in German society. Hitler himself shared some of these same concepts just a few years later in his publication *Mein Kampf* in November of 1923:

Those who are physically and mentally unhealthy and unworthy must not perpetuate their suffering in the body of their children. In this the folkish state must perform the most gigantic educational task here. And some day this will seem to be a greater deed than the most victorious wars of our present bourgeois era. (Hitler 1923)

This rhetoric, naming people with disabilities as unfit, unhealthy, and unworthy, became the foundation for Nazi ethics, soon transitioning into the medical school curriculum where it propelled the goals of the Nazi Regime.

German students and the German people overall, were eager to embrace the messaging of the Nazi Party that promised them a stronger, healthier, and purified future. A “leading Nazi medical authority and a zealous advocate for sterilization,” Gerhard Wagner, “denied any such moral conflict in doctors.” In a popular newspaper column titled “Life or Death” published by the Nazi Party, it was noted that “the life of the nation took precedence over ‘dogma and conflict of conscience” (Lifton 1986, 29). This is best exemplified in the reaction of medical professionals involved in the T4 Program, a program that euthanized people with disabilities in experiments for mass gassings. The experiments conducted during the T4 program led to the methods that later took the lives of over 6,000,000 Jews. When the T4 program was eventually halted and repurposed for killing people in concentration camps on a much larger scale, the medical providers who had performed the eugenic experiments continued their work unsupervised. The actions that took place became known as “wild euthanasia” because the individuals carrying out the procedures “could now act on their own initiative concerning who would live or die” (Lifton 1986, 96). This goes to show how deeply rooted medical concepts continued to control their actions. Even without direct order to kill innocent patients, these medical providers were eager to continue the work of the Nazi Party and play their part in cleansing the *Volk* of those with undesirable traits.

Rudolf Ramm, a professor in the medical school at the University of Berlin, channeled the rhetoric of Alfred, Hoche, and Hitler into an education manual that “proposed that each doctor was to be no longer merely a caretaker of the sick but was to

become a ‘cultivator of the genes,’ a ‘physician to the *Volk*,’ and a ‘biological soldier’” (Lifton 1986, 30). Ramm’s publication, “Medical Law and Professional Studies,” (MLPS) became a mandatory part of medical education, refocusing the commitment of doctors from their individual patients to the much more valued health of the society as a whole. Targeting the medical field and students in particular was effective because they were joining the Nazi Party in significant numbers due to “resentment and hate against the reality of Weimar democracy” following World War I (Friedlander 1995, 217). The curriculum of medical students “included newly designed lectures in racial hygiene, the science of heredity, population policy, military medicine, and the history of medicine” (Bruns and Chelouche 2017, 591). As Ramm stated himself, its goal was to cause “a change in the attitude of each and every doctor.” He suggested that to become a medical provider, a student “must not only be a Party member on the outside, but rather must be convinced in his heart of hearts of the biological laws that form the center of his life” (Lifton 1986, 32). This practice of utilizing language from the field of medicine became a part of the Nazi ideology as a means to validate their actions, in this case describing their “extermination policies as necessary surgery” (Friedlander 1995, 218). This new curriculum instilled an ethical standard for the education of medical students, which was “particularly suitable for promoting Nazi ideology to medical students” and made the eugenics movement of World War II possible (Bruns and Chelouche 2017, 591).

Additionally, one of the overarching goals of the courses taught using Ramm’s publication was to provide medical students with “an understanding of both the written and unwritten laws of the medical profession and of doctors’ ethics” (Lifton 1986, 13). The revised curriculum that included MLPS was intended to explicitly create a “new type of physician.” This physician would be trained to internalize and implement the

Nazi biomedical vision of a homogeneous and powerful people (*Volk*) in his daily work. It involved shifting the focus of ethical concern and medical care away from the individual patient and toward the general welfare of society (Bruns and Chelouche 2017, 592). This was a crucial tool for the Nazi Party to implement its goals and practices on a large scale. Educating new students with a revised ideology, gave the Nazis incredible power. In 1939, the German Regime oversaw 28 medical schools, 13 of which adopted Ramm's educational methods. By 1944, 25 out of the 28 were conducting Ramm's medical training (Bruns and Chelouche 2017, 592). A doctor later testified that "the Nazi embrace of Hippocratic principle [was] 'an ironical joke of world history'" (Lifton 1986, 32). The Nazis reworked the system to fit their goals, ensuring that doctors felt like they were following the rules. The "killing order was euphemistically called an 'authorization' to 'treat' the child [...] the term 'treatment [Behandlung]' was used simply because words such as 'to kill' were considered too revealing" (Friedlander 1995, 57). The Nazis used consequentialism to shape medical care, claiming that the end—a pure *Volk*—justified the means—killing people with disabilities. The German people were so desperate to rebuild themselves and their country that this was accepted as a reasonable sacrifice for the sake of their peoplehood. Medical professionals became tools to remove the illness of the society, rather than providers of these goals on an individual level. Nazi controlled society, in this way, became homogenous in their need to purify and gain strength. Removing the deviants and those who would taint the German image were considered reasonable and justified.

It was of the utmost importance to the Nazi Party throughout their use of euthanasia practices to maintain an illusion of medical necessity. From the start of their control over Germany, they appointed medical professionals to sit on the courts which



made decisions about sterilizations in an effort to “reflect the desired combination of medicalization and Nazi Party influence” (Lifton 1986, 25). The process deciding who would be sterilized through the courts or which infants would be euthanized due to physical abnormalities was always spearheaded by a doctor. The choice of which gas to use for mass murder plots was agonized over because it was feared that such practices veered too far from the “medical point of view” (Lifton 1986, 72). However, the prognoses provided for decisions about whether to euthanize were often based on the least favorable prognosis provided. Sometimes even the auditing physicians who consider a condition incurable that the patient’s primary care physician did not even consider to be serious (Friedlander 1995, 57). Even the way families were notified of the passing of their family members, who in actuality were euthanized, was masked in made-up medical complications (Lifton 1986, 74). The physicians would seek consent from parents or guardians for unusual surgeries that they said the child needed and would consider this consent for euthanizing child, as these children often ended up “unexpectedly” dying during such operations (Friedlander 1995, 57).

Every step of the way, the Nazis made sure that their justifications were airtight and in-line with the new standards of medical practice that they instilled in medical education. The Nazis’ horrific actions highlight the immense importance of medical education and the impact of a change in vocabulary on the change in thought and, therefore, the treatment of an extremely vulnerable population. The system of ethics was rigorously adjusted to utilize preexisting societal structures and convince the public and practitioners that the ends justified the means. This system was ethical manipulation was particularly effective because it took advantage of preexisting negative notions towards people with disabilities. People with disabilities were already separated from

society, hidden away in institutions. The Nazis just took this mentality a step further and suggested that rather than hide them away and allow them to continue to waste resources, they just rid society of the burden altogether. They convinced medical students that the murder of innocent citizens was ethically sound by exploiting existing assumptions that people with disabilities did not have a place in society and it was their professional duty to rid the society of the disease that was people with disabilities.

### **Modern Eugenics**

What can be learned from the immeasurably misguided decisions of the Nazi Regime in their eugenic practices is that patterns of language can be manipulated to motivate certain perceptions and actions. While it is often apprehensible to draw parallels between the eugenics movement initiated by the Nazis and certain practices in modern times, it is necessary to examine the similarities. There are several correlations between the language used by the Nazis to dehumanize the targets of their eugenic practices and the language used today in conversations about modern forms of eugenics. Practices such as selective abortion and physician facilitated death are comparable to eugenics in many cases, often sharing the same goals of removing the unwanted from the fabric of society. Selective abortion is ethically different from abortion otherwise because “ending a pregnancy to which one is already committed because of a particular diagnosed disability forces each woman to act as a moral philosopher of the limits, adjudicating the standards guarding entry into the human community which she serves as normalizing gamekeeper.” In this way, thinking about selective abortion requires women to probe their own biases and consider how social pressures create and enforce certain stereotypes (Rapp 2000, 131). Further, “critics of genetic engineering argue that

human cloning, enhancement, and the quest for designer children are nothing more than ‘privatized’ or ‘free-market’ eugenics” (Sandel 2009, 68). Modern advancements in technology and medical practice have allowed greater opportunity for parents to make more active reproductive choices. With such power and opportunities, however, comes even greater necessity to uphold appropriate ethical standards to ensure that the choices of the past are not repeated.

The “technological progress and clinical knowledge have increased the limits of what is possible in medicine,” allowing for the health and wellbeing of many who would have previously died, but also creating space for decision making that requires careful ethical evaluation (Janvier & Watkins 2013). While prenatal screening has been widely accepted as a means to allow parents more reproductive freedom or to better prepare for any challenges their future child might face, it also perpetuates discriminatory practices by purposely avoiding the births of fetuses diagnosed with disabilities. In using “visualizing technologies such as amniocentesis,” the resulting knowledge “discriminate[s] between the normal fetus and the pathological fetus,” which produces “disabling information and knowledge *in utero*” (Hughes 2015, 81). The issue is not that “advances in medical knowledge and technology have not helped many people,” but the evidence suggests “that medicine is now also making a lot of people sick, in new, and sometimes intractable, ways” (Allen 2015, 97). Medicine often uses a form of rhetoric that enforces a socially constructed conception of the “normal body” and “normal health,” creating challenges in approaching bodies that do not match these descriptions. Pointing to Rosemarie Garland Thomson’s work *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*, she “considers ‘the will to normalize’ such bodies as the drive to expunge human differences, to ignore the

messiness and non-uniformity of nature, and to control, shape, and regulate all bodies” (Taylor 2015, 373). Treating bodies and different forms of health according to antiquated norms, leads to inequitable health services and outcomes for those who are not included in the designated normal.<sup>5</sup>

These modern forms of eugenics are supported by the bioethical principle of autonomy, which respects people’s control and ability to make decisions for their own bodies and lives. While the Nazi’s forced eugenics practices clearly disregarded patients’ needs and desires, modern eugenics are justified by their attention to patient autonomy. As opposed to the consequentialist approach to ridding society of people with disabilities that the Nazi’s used, modern Western science utilizes a more principled approach. While the latter, in theory, could be more ethically sound in dealing with the medical care of people with disabilities, in the manner it has been practiced retains some of the problematic features of the Nazi practices. Modern advancements in medical technology and further emphasis on patient autonomy have allowed a move towards practices that can be called consensual eugenics. Particularly in cases of selective abortion, where a pregnancy is terminated due to a disability diagnosis, it is hard to ignore the similarities of the language used and that of Nazi doctors. During the Holocaust, the Nazis used language such as “sub-human,” “parasites,” and “mass” to describe Jews. The killing of Jews was considered an “evacuation” of a problem, and

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<sup>5</sup> This is particularly apparent in racial inequities in health care, and emerging literature is suggesting similar patterns for those with disabilities as well. Several studies of racial disparities in health care, with a particular focus on infant and maternal mortality rates show disproportionality high mortality rates among black women and infant (Petersen et al. 2019). Further, recent research including measures of health in the medical field, such as Quality-Adjusted Life Years (QALYs) have proven effective in devaluing the life of people with disabilities in medical settings due to their disabilities and then ensuring difficulty in acquiring necessary medical assistance for continued survival. According to the normal defined by QALYs, people with disabilities are far from normal and are essentially punished based on these antiquated norms of what is or is not a healthy body (National Council on Disability 2019).

torture was understood as “medical research.” Language used in discussions about abortion follows a similar pattern. Unborn fetuses are often considered to be “sub-human” and are referred to as a “mass of tissue.” The removal of a fetus is sometimes also referred to as an “evacuation” of the fetus from the womb (“Abortion: The Hidden Holocaust” n.d.). These subtle biases are made more explicit in conversations concerning disability diagnoses, rendering the fetus inhuman. Upon deeper examination, however, “normativity peeks out from behind the friendly face of flexible normalism” and normativity become the framework used in making these difficult decisions (Waldschmidt 2015, 196). In *The Disability Rights Critique of Prenatal Genetic Testing*, Erik Parens and Adrienne Asch write about the “perception within both the medical and broader communities that prenatal testing is a logical extension of good prenatal care: the idea is that prenatal testing helps prospective parents have healthy babies” (Parens and Asch 1999, 1). While prenatal testing has given much more freedom to parents and autonomy in their reproductive choices, it becomes contentious when prenatal testing and more liberal practices of abortion is used in conjunction with the problematic words used by medical professionals, becoming a tool for identifying and terminating pregnancies of fetuses with disabilities.

The language used by a medical professional to deliver and discuss the news of a disability diagnosis prenatally is vital to the promotion of ethically sound and autonomous decisions by parents. In their research on diagnoses of severe genetic disorders, Annie Janvier and Andrew Watkins wrote that “lethal language leads to lethal decisions” (Janvier and Watkins 2013, 1115). Despite being charged with providing parents with well rounded, unbiased, diagnostic information, evidence suggests that “when disabilities are involved, both trained genetic counselors and others who deliver

genetic information do not always live up to that commitment” (Parens & Asch 2003, 40). The depiction of disability in the medical setting, particularly when it leads to the abortion of diagnosed fetuses, is considered problematic because it indicates that a life with disabilities is less valuable than a life without one. Those living with disabilities argue that having a disability, “need not be detrimental to an individual’s prospects of leading a worthwhile life, or to the families in which they grow up, or to society at large” (Parens & Asch 2003, 40). As such practices become increasingly more common, the inherent discrimination imbedded in the process will become normalized too (Faden et al. 1987, 288). Collectively, the disability rights movement and feminist scholarship agree that while there is no definitive response to prenatal screening, there is clear consensus that “public support for prenatal diagnosis and abortion based on disability contravenes the movement’s basic philosophy and goals” (Parens & Asch 2003, 40). Prenatal diagnostic testing introduced a new method of disability discrimination and an ethical burden on expecting parents to be the guardians of a minority group they would not necessarily have any affinity towards. Further, in consultations, concepts of normalcy are applied to human genetics so as to dramatize epidemiological risk, essentially creating hereditary laws that dictate parents’ decision but masked autonomy (Waldschmidt 2015, 204). In doing so, the medical system supports the notion that parents are making the right choice in choosing not to continue the pregnancy of a fetus with disabilities. Together with the verbal sterilization of those who are born with disabilities, the medical system continues to enforce the grounding goals of the eugenics movement.

Prenatal diagnoses started a change in the responsibility to protect people with disabilities from a societal level to the individual level of parents. With this new

technology, “the birth of a child with a disability now increasingly becomes a matter of conscious choice, since the option to detect and terminate an affected pregnancy is available” (Gillam 1999, 165). These newly available choices require the medical care provider supporting the family to act with the utmost ethical consciousness, so as not to sway parents based on personal biases. Research suggests that there is not significant “discussion of the cultural constraints and resources within which different pregnant women and their families (or genetic counselors themselves) may be operating in their training” (Rapp 2000, 57). There are many variables involved in these decisions, both on the part of the parents, medical care provider, and societal pressures. Existing studies based on the limited available prenatal diagnoses indicate that many parents abort fetuses with disabilities due to the lack of knowledge about disability in conjunction with biased or underlyingly negative information provided by medical professionals (Fox & Griffin 2009, 845). This normalizes the concept that a life with disability is not a viable or valuable life and that society has the potential to eventually eradicate it altogether. Choosing to abort such fetuses, over time, threatens the reduction of the size of the people with disabilities often targeted by the medical field, such as Down syndrome. Further, it can also impact the value attributed to those already living with the disabilities, suggesting by trying to eliminate the disability that the lives of those who already experience the disability are lives not worth living. As this sort of testing becomes continuously more common, it will be increasingly important for medical professionals to carefully consider the language they use in these conversations (Asch 1991, 1950).

As medical ability to preemptively diagnose potential risk of disability increases, it is necessary to consider the implications of these technologies. No child is ever going

to fit the exact picture imagined by that child's parents. A preemptive diagnosis of disability quickly clouds that prediction, even if such expectations would never be actualized without the presence of a disability as well. Though this section generally seems to argue against the abortion of fetuses diagnosed with disabilities, that is not exactly the case. In the end, there are many justifiable reasons to abort a fetus upon the diagnosis of a disability, whether it be a financial burden the family could not afford or an emotional or mental load they are unprepared to take on. Such choices might even be considered noble for a parent who has identified that they would be unable to provide the child with necessary medical and financial needs. Additionally, in some cases, the pregnancy would be terminated regardless of the results of the amniocentesis or other forms of genetic testing. It is not the place of any person outside of those participating in the decision to criticize or judge a choice based on assumptions of why that choice is being made. The issue at hand is what factors within these conversations with medical professionals might influence parents' decisions to terminate the pregnancy. If the genetic counselor is solely sharing the medical traumas that could occur to the parents' future child or giving outdated or biased details about the expected life of their child, parents are forced to make decisions based on faulty and/or biased information. Therefore, it is crucial that medical providers give parents the best information possible for them to make decisions unencumbered by the often-discriminatory notions imbedded within medical rhetoric. For this to happen, changes need to be made to the way medical professionals are educated to treat and view people with disabilities.

The way these forms of modern eugenics are treated in several of the countries directly involved in the Holocaust indicates a newfound recognition of the responsibility medical professionals have to protect their patients and ensure the atrocities of the Nazi



doctors do not reappear. Likely a result of the genocide that took place during the Holocaust, stricter laws in central Europe, including in Germany, Belgium, and France make abortions very difficult to approve whether or not they have a disability diagnosis (“Europe’s Abortion Rules” 2015). Likewise, the countries most affected by the Nazi Regime have stricter bans on assisted suicide than do countries on the outskirts of Europe, like the Netherlands, which also is generally more politically liberal (Mullins 2016). In Germany voluntary euthanasia and late term abortions are strictly prohibited. Further, research has suggested that in Germany, “counselors seek to practice a nondirective approach in order to avoid any suspicion that they engage in the eugenics of the past” (Waldschmidt 2015, 204). However, neighboring countries, including the Netherlands, have liberal laws that allow assisted suicide and abortion to be practiced regularly (Guardian Staff 2017). While assisted suicide is not yet widely practiced in the United States, abortions are routine and becoming increasingly normalized.

Moreover, a stigmatizing language phenomenon is the desexualization of people with disabilities, a modern-day form of sterilization. The “persistent and damaging myth that people with disabilities don't have sex” (Trace 2012) is prominent in modern societal views of people with disabilities.<sup>6</sup> Such infantilizing stereotypes of people with disabilities encourages a mental sterilization of the population. Although sterilization is

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<sup>6</sup> A recent example comes from a Netflix documentary series called *Love on the Spectrum* which documents the experiences of several adults with autism spectrum disorder as they date and experience relationship milestones like moving in with a partner or getting engaged. Although the show discusses adults—of varying degrees of independent, all of whom work, drive, take care of themselves, and other markers of Western adulthood—in romantic relationships, only once in the five hours of the show was sex mentioned, and when it was it was in very indirect way, asking a couple if they had consummated their relationship. But when the couple did not understand the phrasing, rather than rephrasing the question in a way that was clearer to them, the producers just moved on from the topic altogether. This is a common complaint of patients with disabilities who are not only assumed to be incompetent, but assumed not to be interested in or enjoy the rather typical aspects of maturing like dating or participating in intimate relationships.

not forced through means of legality, the language used to discuss people with disabilities essentially achieves the same purpose. For example, in diagnostic meetings with genetic counselors, there are patterns reminiscent of the concepts backing sterilization, such as not allowing those with unwanted characteristics to be reproduced. Such desexualization often occurs in two forms. People with disabilities often experience infantilization both in medical and social contexts, where people are referenced in child-like terms or talked to like children well passed the appropriate age (Robey, Beckley, and Kirschner 2006). Secondly, people with disabilities, even at an age where they are beginning to express interest in dating or are going through puberty are not given appropriate sex education. It is often assumed that a person with disabilities cannot or will not be able to participate in romantic or sexual relationships, so the topic is avoided all together. Some even believe lack of sexual education for people with disabilities is the cause of alarmingly high rates of sexual assault against those with intellectual disabilities (Shapiro 2018).

As medical technology continues to advance and become increasingly accessible, so too is the concern about how the use of such technology will, intentionally or unintentionally, harm people with disabilities. Many find that the use of genetic technology to enhance human children is uncomfortably similar to the eugenics movement, which peaked in popularity during World War II (Sandel 2009, 51). Though the aggressive means of achieving the perfect, pure nation under the Nazi Regime has been discredited and condemned, some of the underlying aims of eugenics continue in modern medical practice, masked in new technologies and increased patient autonomy. However, concepts of normalcy still remain even in today's society and are deeply imbedded in much of the medical rhetoric surrounding certain practices, such as

selective abortion. The conversations that take place surrounding a disability diagnosis “produce disabled subjects in utero” and continue to enforce the same suggestions of the Nazi’s eugenics movement that lives with disabilities are less valuable and should be reduced (Hughes 2015, 81). In the decades following the medical trials that took place after the Holocaust, the “governance by normalization” has increased in influence. This sort of governance, defining and depending on concepts of normality has the “ability to redefine the concept of normality and to enforce normality in social practice via discourse, operative procedures, and policies organized around an identity” (Waldschmidt 2015, 195). In disability diagnoses today, “the physician’s expertise in the child’s medical care creates a conversation about the medical implications of the disability rather than the potential and ability of the infant” (Dworetz 2014, 22), continues to push people with disabilities outside the boundaries of normalcy.

Many of the issues with medical rhetoric as it pertains to disability are deeply imbedded in language and may appear innocent on the surface. When considering the conversations that occur between medical professionals and families upon the diagnosis of a disability during pregnancy and the difficult conversation that ensues, the bias present in the language and presentation is almost invisible. For, “only on second consideration does it become clear that such cases also involve decisions about what is normal or abnormal in our society” (Waldschmidt 2015, 196). The problematic language results from the long outdated medical model of disability which still prevails in medical settings. This model suggests that the issue of disability is the person with disabilities, rather than considering the ways in which societies are constructed to create and perpetuate disabilities. Within medical settings there needs to be a change in “the understanding of disability from the medical to the social model will require an

adjustment in the language used to portray and appreciate disability” (Dworetz 2014, 143). Only when the attitudes of medical providers change will the rhetoric and the quality of care afforded to those with disabilities improve as well.

### **CHAPTER 3: Implementation of Disability Cultural Competency**

*I used to try to explain that in fact I enjoy my life [...] But they don't want to know. They think they know everything there is to know, just by looking at me. That's how stereotypes work. They don't know that they're confused, that they're really expressing the discombobulation that comes in my wake. (McBryde Johnson 2003)*

#### **Down Syndrome Diagnoses, A Case Study**

Down syndrome is a great case study of treatment of and descriptive language for people with disabilities because it includes many of the aspects of disability upon which disability scholarship focuses. People with Down syndrome have visibly identifiable characteristics of having a disability, typically have cognitive disabilities, have several comorbid medical conditions, are associated with the word *retard*, and can be diagnosed prenatally. Further, Down syndrome is a better-known disability among the general public. Here, prenatal diagnoses of Down syndrome and the ensuing conversations between medical care providers and parents will be studied. In relation to the earlier discussion of the word *retard*'s transition from patient classification to pejorative, this case study will provide further contextualization. This section will consider how language, inherent biases, and lack of disability cultural competency impact what information provided in a Down syndrome diagnosis, which in turn may affect parents' decisions to continue or terminate a pregnancy.

Down syndrome is a classified disability that is often associated with the word *retardation* and, to this day, the cognitive symptoms are often referred to as *mental retardation*. The name Down syndrome was born out of a desire in the mid-twentieth century to avoid association with the language of disability recently deemed problematic. Previously, Down syndrome was referred to as "Mongolian idiocy"

according to Jerome Lejeune, a French geneticist's original description of the condition. In 1961, "several renowned genetics experts wrote to the British medical journal, *The Lancet*, requesting that the name used to describe having three copies of chromosome 21" be renamed for John Landon Down, a physician involved in the condition's identification and classification (Rochman 2017, 104). Though the name seemingly avoids the issue of misappropriation, having been named after a person, the word *down* in and of itself has frustrated those with Down syndrome and their families, because of its potential to indicate unhappiness or lesser status. In previews for the Emmy Award winning series *Born This Way*, which documents the lives of several adults with Down syndrome, one of the show's front runners jokes that he prefers to call his condition "up syndrome" because he thinks that positivity better describes him and others who have Down syndrome.

While people who have Down syndrome often do lead productive and happy lives, Down syndrome's negative perception is reflected in public attitudes and in abortion rates. Generally, abortion rates for fetuses diagnosed with a disability are higher than the national average abortion rates. While the average abortion rate in the United States is roughly 1.5% (McCammon 2017), disabilities like Down syndrome and spina bifida are aborted at the much higher rates of 87% and 64% respectively (Cossey 1998). More recent statistics show a decrease in abortions of fetuses diagnosed with Down syndrome to 67%, but alarmingly high rates of such abortions are documented as 77% in France, 98% in Denmark, and nearly 100% in Iceland (Wakeman 2016). As Dr. April Dworetz, a neonatologist, bioethicist, and associate professor of Pediatrics at the Emory University School of Medicine wrote in her master's thesis about conversations between doctors and parents during a diagnosis of Down syndrome, "the physician's

expertise in the child's medical care creates a conversation about the medical implications of the disability rather than the potential and ability of the infant" (Dworetz 2014, 22). Though people with disabilities have become more visibly mainstreamed in modern society, perceptions about disability in many cases have not wavered.

The field of disability studies is rooted in the core values and scholarship of women's studies and feminist theory. As such, the field of disability scholarship typically recognizes that parents can and should have the right to make autonomous decisions about their bodies. As Dr. Marsha Saxton, Director of the World Institute on Disabilities, writes, "the reproductive rights movement emphasizes the right to have an abortion; the disability rights movement, the right *not to have to have* an abortion" (Saxton 2017, 88). While some disability advocates argue that no fetus should be aborted based on a disability diagnosis, the majority agree with Saxton's argument. The issue of selective abortion becomes, in many cases, a result of the societal pressures that indicate lives lived with a disability are less valuable, less desirable, and certainly not something one should wish on their child. This complicates true autonomy and can subliminally encourage the termination of pregnancies when the fetus is diagnosed with a disability. When parents receive such a diagnosis, a lack of appropriate education and informational tools does not help these outside pressures. In conjunction, social influences and poor disability cultural competency impact the decision-making process and undermine parental autonomy. Parents do have the right to make their own decisions, but they should be just that: their own.

Every parent enters medical encounters with varying background, expectations, knowledge, and values. When a diagnosis of disability becomes a component of the dialogue between a medical care provider and their patient, it is met with the unique

context of the parents' specific ideology and life circumstance. In these complex situations, it is the medical professional's role to provide parents with medical information regarding their pregnancy that is substantial, specific, and unbiased. While it has not always been the case, it is necessary that doctors give unbiased opinions and help contextualize how a diagnosis might interact with a family's specific lives, expectations, and values. It is a medical professional's responsibility to provide this information with sensitivity to the range of plausible parental reactions and to personal biases guiding the parents' reactions as well as their own. Omitting certain information, like life experiences and successes of those who have lived to advanced ages with Down syndrome, are exemplary of how the medical model prefers to think about Down syndrome (Skotko, Kishnani, and Capone 2009). Often, the medical presentation of a child diagnosed with a disability suggests "that a disabled neonate is his syndrome" (Dworetz 2014, 24). Simply providing a list of medical symptoms and problems associated with the disability paints a very specific and unflattering picture of what raising a child with Down syndrome might be like. Parents' memoirs and personal narratives abundantly clarify that this is not an accurate depiction of raising a child with Down syndrome. Though these conversations have evolved over time and are less discriminatory in nature than they have been previously, there is still much progress to be made.

In addition to the many studies of potential harms and importance of conversations surrounding prenatal diagnoses, it is also important to look to the other side of the story. To better conceptualize parents' lived experiences of these diagnoses, four parent memoirs will assist in exploring these issues. Each parent's memoir provides a unique perspective on their journey through receiving a diagnosis, their process of



coming to terms with the information, and the guidance, or lack thereof, they were provided in the first months and years of their children's lives. While these memoirs only share perspectives of parents who chose to keep their child upon diagnosis or received the diagnosis after the child was already born, many imagine how the prenatal diagnosis and option of termination may have affected their decision to carry the pregnancy to term. These stories are honest and personal. Though the introduction made a strong case that people with disabilities are the rightful ones to construct the knowledge about their experiences of disability, they cannot remember the experiences of their initial diagnoses. For the purpose of this case study about the process of giving and receiving a disability diagnosis, the perspective will turn to the perspectives of parents as they are the only ones who can recall these particular aspect of the disability experience. The stories shared by parents in the early moments of their children's lives often foreshadow the experiences their children will one day be able to share themselves. In fact, parents who themselves have a disability often experience extreme prejudice and judgement in their choices to reproduce. This particular project will not delve into that perspective, but it is another important one to note. While the following memoirs are not representative of *every* parent experiencing the trials and tribulations of raising a child with Down syndrome, they are representative of the stories typically untold upon medical diagnoses of Down syndrome. As many of the parents remark in their memoirs, they wish these stories had been available to them when they were coming to terms with their own children's diagnoses.

Rachel Adams was involved with the field of disability studies long before she had a direct personal connection. Adams wrote her dissertation about the historic "freak shows" that are very important to disability scholarship. While the stories of the "freak

shows” have been told and retold countless times, Adams took a different angle in her work. Rather than focusing on the freak shows and their implications for those with disabilities, she turned to the subjects of the shows themselves. She studied the personal narratives of the “freaks,” and tried to piece together their lived experiences and personal bodily perceptions. While she was well versed in concepts of disability scholarship, this did not prepare her for the diagnosis that came shortly after the birth of her second son, Henry.

In her memoir, *Raising Henry: A Memoir of Motherhood, Disability, and Discovery*, Adams wrote about the experience of receiving a Down syndrome diagnosis shortly after her son’s birth and reckoning with this diagnosis. Her son was not diagnosed immediately, but she felt that something was different than the birth of her first son, even wrong, right away. Though she and her husband snapped away energetically on their camera when their first son was born, the camera, readied to document the occasion, remained untouched when their second son was born. Adams recalls that “there was something about him that didn’t quite make sense,” and considers that maybe she “knew all too well what [she] was seeing” (Adams 2014, 5). However, she did not put a name to it, and neither did the physician who delivered the baby. Adams figured that her doctor likely knew that her baby boy may soon be diagnosed, but “breaking the news would be someone else’s job” (Adams 2014, 6). In this first instance, a reluctance to acknowledge the potential disability shows a sense of denial on Adams’ part that her son might not live up to the expectations she had likely already drafted in her imagination. Her doctor’s silence, however, exhibited an unwillingness to address a diagnosis head on and created a sense of mysterious concern in a moment that should be joyous for parents.

Soon after his birth, Henry was assessed and Adams and her husband were informed their baby likely had Down syndrome and would need to be taken to the neonatal intensive care unit (NICU) for further observation. Though the doctor tried to reassure Adams that everything would be okay, this seemed to starkly contrast that the baby would need to visit the NICU. They were asked if they had any questions as this was “a lot to take in,” but Adams was overwhelmed by her shock and was not able to verbalize any of her many questions. While commendable that space was made for questions, it is difficult for a parent receiving an unexpected diagnosis to know where to start. The doctor, seemingly not wanting to overwhelm the parents, could have also directed them through some of the information that might be helpful to them in processing this information rather than little to no information at all. Adams remembers she was unable to stop crying out of worry even though she “didn’t feel much of anything for him,” after they took Henry to the NICU. Of the experience, she says: “I was mourning the loss of the son I thought I was going to have and the family I imagined we would be” (Adams 2014, 11). This is not an uncommon feeling for parents who receive a disability diagnosis. There often is a process of mourning the life they imagined for their child and the assumption that a disability diagnosis shatters all of those dreams. However, this does not need to be the case. While a disability diagnosis will certainly alter parents’ expectations for their child, it is unusual for any child to ever perfectly fit the mold imagined for them. As these are common experiences of parents receiving such a diagnosis, medical care providers can be better prepared to support parents through the different phases of reaction and provide them with the information they need to understand the situation rather than imagine the worst possible outcome.

Upon the diagnosis of Down syndrome or any other disability, appropriate educational materials provide parents the tools to remold their hopes to better fit their child. However, upon her own search for materials, Adams “found nothing useful in any of the prenatal guides” that she collected following Henry’s birth. Within the books she found, she “was struck by the fact that every one of them referred to the likelihood of conceiving a fetus with Down syndrome as a ‘risk,’ a word that implies a danger to be avoided.” Reading these words in reference to her son, she wondered “about what difference it would make if they used the word ‘chance’ instead” (Adams 2014, 23-4)

Adams continued,

These are just words. Some people might ask what difference it makes whether we say a baby is retarded or cognitively delayed. It makes all the difference in the world, since one label implies a static and unredeemable essence, the other a malleable condition that can be shaped by society and environment. (Adams 2014, 24)

Adams attention to the words used to describe her newborn baby are indicative of the experiences of many parents who receive a similar diagnosis soon after birth or during pregnancy. To a medical professional or layperson, these words might seem unassuming and factual, but when attached to a child with a future and a loving family, it turns the baby into a mere medical diagnosis and nothing more. This is an unpleasant way for a new parent to feel and illuminates the many problems with the terminology used to discuss disability medically. Adams goes as far as to call the descriptions she found of Henry’s condition “grotesque and clinical” (Adams 2014, 24). Adams mused,

As if the baby could be reduced to a set of predictable features that had nothing to do with his parents’ genetic information [...] I was dismayed to see people with Down syndrome referred to as ‘suffering’ or ‘afflicted,’ to see that Down syndrome was lumped together with genetic diseases that cause intense pain or

fatality, to find it frequently described only by a list of physical characteristics and the risk of ‘mental retardation.’

Adams questioned whether her “baby’s appearance and personality [were] really so predictable?” (Adams 2014, 25). As with any child, this is of course not the case. There is no way to predict a child’s development, and medically enforced parental presumptions insinuate people with disabilities to the outdated stereotypes often associated with the word *disability*. There is a range of expectations that come with any disability diagnosis, but often only the worst of those possibilities is presented to parents. Medical professionals can better balance the information they provide, both give information and present the range of potential while also avoiding stereotyping.

Adams spent her first months as Henry’s mother trying to discern her beautiful baby boy from the “avalanche of symptoms and characteristics” to which the medical professionals and baby books were trying to confine him. She wondered how they would be able to give Henry the space to grow into his own identity independent of his Down syndrome diagnosis. Adams wanted to extricate her child from “the category that others are already using to define him” (Adams 2014, 28). When all their conversations were about symptoms and potential problems, it was hard to think about what his future might hold. Adams and her husband certainly were not given any guiding examples about what Henry’s life and their life as his parents might look like. Even when she asked a social worker at the hospital about support groups they might be able to join, the woman “seemed at a loss” and Adams felt like she was alone in the world as the only parent to a child with Down syndrome (Adams 2014, 33). Adams’s experience depicts the prevailing issue of melding symptoms of a diagnosis to the object of diagnosis. While certain medical facts are likely for a child with Down syndrome’s future, there is so

much more to their life than just a list of symptoms. It is important, even in the beginning of a child's life, to see the baby as a baby first. Not a Down syndrome baby. Not a baby with Down syndrome. Just a baby with an unknown future, who will have health needs, who will experience milestones and achievements, and lots of love from their parents.

George Estreich, an author and stay-at-home dad, experienced a similarly future focused and medicalized conversations during the first few days and weeks after his daughter Laura's diagnosis. Estreich concludes the introduction to his memoir *the SHAPE of the EYE* with the powerful recognition that he felt "two kinds of stories" were told about Laura. He continued, "in one, she seemed to be a developing child. In the other, she seemed not even human. She was a defect, a tragedy, an abnormality. I did not see how she could be both. It was as if Theresa had given birth to a blur" (Estreich 2013, xvi). Estreich's experience of his daughter as a "blur," between the daughter he imagined and the one riddled with potential medical problems, built slowly, as his diagnosis experience was not as immediate or certain as many who receive a Down syndrome diagnoses at birth.

Unlike many parents who are bewildered by the suggestion that the newborn upon whom they are doting may have Down syndrome, Estreich and his wife experienced momentary shock which faded quickly to the back of their minds. As the doctor assessed Laura, he mentioned she might have Down syndrome, which received complete silence before it passed over the new parents. Though this project argues for the normalization of disability, glossing over a new diagnosis is not a productive response either. Estreich recalls very little of the experience. Though he suggests the information should be "seared in [his] memory," he does not remember exactly how the

news was delivered. Estreich proposes several reasons he might not remember exactly, such as the overwhelmingness of such information, that it felt unlikely to be true, or that the one identifiable feature that suggested Down syndrome in his daughter, her eyes, could be reasonably explained by his Japanese heritage (Estreich 2013, 2). But two weeks after leaving the hospital and forgetting any possibility of their daughter having Down syndrome, a positive test returned. At that point, the contrast between his baby daughter and the host of medical considerations that would ensue emerged.

When the spell was broken, the child before us assumed her true appearance—or say, instead, that her identity was revealed that the centrifuge performed its necessary separations, and that her appearance was revealed in turn. She was unchanged and transformed. (Estreich 2013, 6)

Estreich does not discuss the resources he and his wife were offered, but they experienced the same limbo between the daughter they imagined and the daughter who sat before them with an unexpected diagnosis. His wife felt “as if [their] baby had been stolen and replaced with a collection of medical problems” (Estreich 2013, 6). While there certainly are medical considerations that must be made upon a Down syndrome diagnosis, they do not need to be the focal point of the identity bestowed upon a newborn baby. Estreich was unable to find any middle ground between the daughter he was doting on and the medical specimen the doctors presented her as. Eventually they, too, learned to love their daughter for who she was, extra chromosome and all, and adjust their expectations.

Estreich discussed the future he imagined for his daughter and how her diagnosis of Down syndrome changed that image:

I felt foolish, bemused. Like it or not, I had constructed a future, one nearly as specific and complete as Laura herself; and that future, that nine-month reverie, was completely, provably wrong. Even as the forty-seventh chromosome added

itself to each cell [...] I, too, had been forming a life. Or, more exactly, a paralife, a hazy projection of new child and altered family. (Estreich 2013, 10)

But Estreich had to learn to see his daughter as more than just her diagnosis, as a child first—as he discusses in one of the chapters in his memoir. For him, the biggest barrier to accepting Laura and seeing her as a child beyond conflating her identity with her diagnosis of Down syndrome. He soon learned, the resolution to this was to just spend time with her. In an interview he gave shortly after the publication of his memoir, he remarked,

I thought for a long time about Down syndrome, what it was and what it meant, what it had to do with Laura. Down syndrome was big news, and I had to process it. But the shock wore off, and Down syndrome became ordinary, and a big part of that was just seeing Laura for who she is. Even when she was an infant, her personality was a force. (Hudson 2013)

Estreich believes that this is an important aspect of a new parent coming to terms with a disability diagnosis, but also an important lesson in disabilities being more welcome across society. He thinks that “if Down syndrome were ordinary in the world, if a commonsense view of dignity and personhood and capability prevailed, then perhaps our early days would have been easier” (Estreich 2013, xv). That is not yet the case, but perhaps one day it will be. And when that day arrives, diagnoses of Down syndrome will not shatter all expectations of a child’s future, but merely to take shape around the child and their own identity and uniqueness.

Michael Bérubé, a Professor of Literature at Pennsylvania State University, was thrown into the community of parents of children with Down syndrome, with an advantage unlike the previous authors: his wife, Janet, is a nurse. She was better prepared for the medicalization that permeated their delivery experience and interactions following their son Jamie’s birth. Down syndrome was not the first



unexpected experience of Jamie's birth; Jamie arrived two weeks early and was quickly followed by "more unexpected things, in rapid succession" (Bérubé 1998, 4). Janet noticed a dangerous arrhythmia in her own heart monitor and started barking orders at the obstetric nurse in the room. Though Bérubé was ignorant of the specific medical emergency, he was immediately aware that something was wrong.

Commonly, babies born with Down syndrome experience heart defects which require major surgeries soon after birth (de Rubens Figueroa et al. 2003). Jamie was born "an unmoving baby of a deep, rich, purple hue, his neck wreathed in his umbilical cord." Bérubé overheard the medical team refer to Jamie as "downsy" during delivery. The use of this casual, nickname for Down syndrome went mostly unnoticed in terms of meaning, but was an inappropriate first indication of the diagnosis that was imminent. The term meant nothing to Bérubé at the time, but he recalls worrying his son was stillborn and his wife might die as their heartbeats remained irregular during labor. His dire expectations painted the suggestion that Jamie might have Down syndrome as a "reprieve," to the thought of losing his wife and baby altogether. However, after the diagnosis was confirmed, Bérubé realized he knew nothing about Down syndrome except that "it meant James had an extra chromosome and would be mentally retarded" (Bérubé 1998, 5). This terminology was not outdated at the time, but left Bérubé completely unaware of what to expect for his child's future. While moments before the diagnosis Down syndrome seemed like a circumstantially positive option, when the implications of the diagnosis sunk in his outlook was no longer optimistic.

Similar to many other new parents of infants with Down syndrome, Bérubé and his wife were left to wait anxiously as their son was taken for a series of tests. Like Adams, they were "told everything was all right for a newborn with Down's," but Jamie

was “transferred from the nursery to the intensive care unit and put on 100 percent oxygen” (Bérubé 1998, 7). This contradiction, once again, provided effective in confusing and scaring the new parents who had yet to fully grapple with the meaning of the diagnosis in the context of their lives. The doctor attempted to comfort Bérubé by emphasizing the divide between healthy and unhealthy, and its association with having a disability or being non-disabled. The spectrum between healthy and unhealthy and Jamie’s placement within it became a constant theme throughout his life. Nineteen years later, Bérubé reflected on this pattern in his sequel memoir, *Life as Jamie Knows It*: “it never occurred to me that anyone would offer him a lower standard of care because of his disability. So it took me longer than I would like to admit, in retrospect, to figure out what was going on with his dentist” (Bérubé 2017, 48). Bérubé felt as if the dentist thought “*C’mon, the kid has Down syndrome, and you’re worried about a little thing like his teeth?*” And this was not an experience he only had at the dentist. He cites similar experiences and implies this was a notion he felt many doctors who saw Jamie as a patient felt when looking at his son. He referred to it as a “deplorable attitude” where the varying medical health professionals saw Jamie first as having Down syndrome and, as such, figured he had more important issues to worry about than measly things like the health of his teeth and eyesight (Bérubé 2017, 49).

Bérubé further considered his early experiences with and initial reaction to Jamie’s diagnosis in his follow up memoir. He wrote,

on the day Jamie was born, my knowledge about people with Down syndrome was so outdated and inadequate that I believed he would have a life expectancy of twenty-one. (That is not a thought I can bear today.) This phenomenon—our process of learning that our expectations for Jamie, and for people with Down syndrome, are subject to constant revision—is very possibly the most important, the most consequential thing we can tell you about our own journey, because of

course prospective parents who undergo prenatal testing and receive a positive diagnosis for Down syndrome make their decisions to continue or terminate the pregnancy on the basis of their expectations about what their child will or will not be able to do, their expectations about the quality of life they and their child can enjoy. (Bérubé 2017, 16-7)

Raising Jaime taught Bérubé that a diagnosis of Down syndrome leaves much more room for growth and expectations than the diagnosis experience suggests. In other words, the expectations set by the medical system limits potential for development and success. If the bar is set low, there will be less motivation to exceed it. He believes that his family's life is "far richer than we could have imagined before Jamie was born" (Bérubé 2017, 16), and has completely changed his perception of Down syndrome. However, the sense of richness Bérubé feels today developed as he witnessed his son's growth and conducted his own research. Over time, Bérubé realized his child's future was unknown as it is with all children. His family experienced challenges along the way, but all Bérubé knows now about life with Down syndrome, he did not know when Jamie was diagnosed. Had he received a more detailed and less medicalized diagnosis about what Jamie's future might hold, Bérubé could have adjusted his expectations sooner under professional, caring guidance and created a more welcoming and openminded environment to bring his son home into.

Amy Silverman is a journalist and managing editor at *Phoenix New Times* and the author of *My Heart Can't Even Believe It: A Story of Science, Love, and Down Syndrome*, a particularly honest memoir about her daughter Sophie. Here, Silverman's work is presented last because of her intensity of experience and painstaking honesty. The other parents ask, "what if my child did not have Down syndrome," but Silverman tackles "what if I had found out sooner." When she first heard the words Down

syndrome spoken in relation to her daughter, Silverman only knew it was a “part of the list of things you didn’t want your kid to have” (Silverman 2016, 14).

Sophie’s diagnosis was a whirlwind experience. Silverman awoke following an emergency C-section to her husband and physician measuring her daughter’s ears as a metric of features associated with Down syndrome. Though she was panic-stricken, as doctors and nurses filtered through her room, Silverman would casually ask their opinions. It seemed the medical professionals identified Down syndrome, but no one would confirm a diagnosis. No one wanted to be the bearer of “bad news.” Repeatedly, the obstetrician and nursing staff told Silverman to wait for the pediatrician to run the tests. Someone offered her the information for a Down syndrome support group, but Silverman refused to acknowledge the possibility that Sophie might actually have Down syndrome (Silverman 2018, 16-18). The pediatrician finally arrived and “quickly announced, ‘I know you are concerned that the baby might have Down syndrome. I’ve heard that some of the nurses think she does. But I have examined this baby, and I can tell you with certainty that she does not have it!’” He said they would run a confirmatory blood test as “a formality” in a well-intentioned attempt to reassure Silverman and her husband (Silverman 2016, 19). While setting up misinformed expectations was a problem in of itself, this initial suggestion of excitement that the child did not have Down syndrome was also misleading and set up the actual diagnosis to be in more severe contrast to the expectations. Asserting that Sophie was fine because she *did not* have Down syndrome enforced what Silverman already believed to be true: Down syndrome made her baby unhealthy and precluded her from a happy life. When Sophie’s diagnosis was confirmed three days later, Silverman thought to herself, “*I have ruined*

*our lives. I had a sick baby, a baby who is going to make us miserable*” (Silverman 2016, 20).

Silverman was sent to a geneticist whom she figured would examine Sophie and tell her “all kinds of things, like how smart she’d be and whether or not we’d have more kids with Down syndrome.” Before the appointment, Silverman had “already figured out that those questions don’t have answers,” but she still wondered, “how was Sophie going to fit into the world?” (Silverman 2016, 1). Silverman was concerned with what she considered “the big unanswerable question,” of how Sophie fit into society, but she “had smaller ones, too,” like whether Sophie would have curly hair like hers (Silverman 2016, 5). Silverman went through an extensive process of defining Down syndrome:

The genetics counselor (and every doctor I’ve talked to and book or article I’ve read) explained it so simply: In the vast majority of cases, something goes haywire during conception (probably having to do with an old mom, according to the ‘expert’) and the fetus winds up with an extra twenty-first chromosome.

This explanation is usually accompanied by a worn-out Xerox copy of twenty-two pairs of squiggly black lines—and one set of three squiggly lines.

Um, yeah, sure. Got it. Now, what the hell is a chromosome again? This isn’t the kind of thing that is addressed during the length of a typical doctor appointment, and it’s sort of awkward to have to admit that you weren’t paying attention that day (week/month/year) in high school biology. Besides, even though it’s all about biology, it turns out deciphering Down syndrome is also a lesson in anthropology and history, with a dose of psychology thrown in. (Silverman 2016, 8)

Silverman’s experience is common of parents to children with Down syndrome. There is no uniform prediction of how life with Down syndrome proceeds, likening the experience of raising a child with Down syndrome to that of raising any other child. It was not until Sophie’s seventh birthday that Silverman came to this conclusion herself. She realized that Sophie was “no longer my daughter with Down syndrome. She was my kid, and I loved her and not because I was supposed to. I can’t tell you exactly what did

it. Time, I guess [...] I finally had a real relationship with Sophie” (Silverman 2016, 7). Silverman finally felt prepared to address, as a reporter, the questions she could not ask when Sophie was first diagnosed.

Silverman admits if current technology, which noninvasively detects Down syndrome in the first trimester, existed during her pregnancy she likely would have terminated her pregnancy. She shares, “it kills me to think that I might have had an abortion simply because I’d never met another person—adult or child—with Down syndrome. I had nothing but the vaguest notion of what the diagnosis meant or what it could mean” (Silverman 2016, 68). To this point, advocacy groups have promoted better educational materials for parents to receive alongside a disability diagnosis, including contacts to parents of people with disabilities and people with disabilities themselves. The goal is for expecting parents to have the opportunity to learn first-hand about the experiences of those living with the disability their future child has been diagnosed with and make a more informed decision. Throughout her memoir, Silverman honestly shares the prejudices and inappropriate language she had to unlearn. She remembers using the word *retarded* as a pejorative and switching lines at the grocery store when a clerk had a visible disability. Silverman recognizes many people feel this way about those with disabilities until a personal interaction shatters the stereotypes.

These four memoirs of raising a child with Down syndrome are representative of their genre and instructive because they elucidate the resultant uncertainty of a Down syndrome diagnosis, encouraging progress. A child’s future is always unknown at birth, but upon diagnosis with Down syndrome, expectations and dreams for the future seem to disintegrate. Parents’ preconceived notions inform their reaction to diagnoses and medicine’s ambiguous and outdated language enforces negative stereotypes. In the

memoirs, parents shared their personal background and how that, in conjunction with the delivery of a diagnosis, shaped their feelings about disability. In each parent's experience, there was clear expression of angst, anxiety, discomfort, loss of hope, and many other negative emotions associated with their child's disability. For some, these came out of their own inherent biases and for all, a feeling of sadness was further enforced if not already present by the delivery of the medical providers. Down syndrome is well-understood and people with Down syndrome live full and meaningful lives, but the language and information used to educate parents inadequately reflects progress.

Dr. Brian Skotko, the founding Director of the Down Syndrome Clinic at Massachusetts General Hospital, notes: "in medicine, our language is sometimes more powerful than our prescriptions... updating our terminology to respect patients' concerns is as important as modernizing our medical offices with the latest clinical instruments" (Wallace 2013). These memoirs clarify the significant advances we must make within the medical and social linguistic frameworks to better begin to reflect the lived experiences of people with Down syndrome at the beginning of life and are incredible resources for medical professionals and new parents of children with Down syndrome. As supplements to imbalanced medical information, memoirs of raising children with Down syndrome prepare new parents for the initial experiences of receiving a diagnosis of disability.

### **Disability Cultural Competency**

Much of this project is built upon cultural competency, which requires further elaboration. Disability cultural competency, as is suggested by this project for use in medical education, was developed by Dr. Rosemarie Garland-Thomson, a Professor of

English and Co-Director of the Disability Studies Initiative at Emory University.

Garland-Thomson's work has furthered Disability Studies and pioneered the emerging field, Disability Bioethics. Disability cultural competency arises from the intersection of critical disability theory and bioethics. Garland-Thomson proposes that society's lack of understanding about the disability experience and its diversity is the foundation of the need for better disability cultural competency. She says, "most people don't know how to talk about disability or how to be disabled," therefore, they do not know how to appropriately treat or care for people with disabilities (Garland-Thomson 2017, 332). Before her work can be discussed, it is necessary to detail the work on which disability cultural competency builds.

Cultural competency first emerged at the end of the 20th century and was expanded in the early 2000s. Its goal was initially to help mental health professionals better identify cultural factors impacting patient experiences by creating better awareness of cultural difference, knowledge of cultural practices, and skills to identify culture within lived experience (Sue, Ivy, and Pederson 1996). In 2000 and 2002 respectively, the Center for Mental Health Services and the American Psychological Association proposed guidelines for cultural competency in mental healthcare. Contemporaneously, the U.S. Department of Health and Human Services and the President's New Freedom Commission on Mental Health recognized the importance of cultural competency (S. Sue 2006). In the past two decades, cultural competency has evolved and further specified the foundational understanding that "when health professionals and patients from different linguistic and cultural backgrounds interact, there is the increased possibility of miscommunication since the participants will be interacting on three levels of remove: medicine, culture and language" (Harvey and



Koteyko 2013, 53). Today, cultural competency is a critical component of all fields of health care.

Garland-Thomson's disability cultural competency is predicated on Jonathan Metzl and Helena Hansen's *Structural competency: Theorizing a New Medical Engagement with Stigma and Inequality*. Metzl and Hansen present structural competency to further emphasize the importance of patient identity and "expressions of illness and health" in medical training. Structural competency identifies social structures that demarcate "race, ethnicity, social class, religion, sexual orientation, or other markers of difference" that impact patient treatment (Metzl and Hansen 2014, 126). Cultural competency includes concepts of structural competency and takes it to another level beyond just identifying the differences that impact patient identities and perspectives. It "emerged during an era when U.S. medicine failed to acknowledge the importance of diversity issues" and has since "helped promote consideration of the impact of stigma and bias into treatment decisions" (Metzl and Hansen 2014, 126). Medical professionals must recognize the social structures that impact their patient's health needs to provide their patients with necessary and deserved care and attention. Metzl and Hansen assert medical training must better address "how such variables as race, class, gender, and ethnicity are shaped both by the interactions of two persons in a room, and by the larger structural contexts in which their interactions take place" (Metzl and Hansen 2014, 127).

They propose a five-step training process for medical professionals to address structural competency in medical care:

1. Recognizing the structures that shape clinical interactions
2. Developing an extra-clinical language of structure
3. Rearticulating "cultural" presentations in structural terms

4. Observing and imagining structural intervention
5. Developing structural humility

Through such a training, the guidelines work to support perspectives that move beyond just being aware of culture within medical settings but delve deeper into how those cultures are tangled with structural inequality and bias (Metzl and Hansen 2014, 128). Metzl and Hansen recognize cultural competency as fundamental to recognizing structures which enforce culture and impact health care, but share warning to not let this recognition further enforce the cultural expectations it seeks to ameliorate. They emphasize Dr. Skotko's argument for encouraging language to evolve in regards to the current times and needs of patients. The proposed curriculum for structural competency helps practitioners develop skills that are considered the start of these important conversations and instigators of further thought and evolution. Medical providers must recognize that in considering how structures impact their patients and themselves, they "are at once speakers and listeners, leaders and collaborators, experts and benighted" (Metzl and Hansen 2014, 131).

From Metzl and Hansen's proposal for structural competency, Alicia Ouellette's *Bioethics and Disability: Toward a Disability Conscious Bioethics*, and Jackie Leach Scully's *Disability Bioethics: Moral Bodies, Moral Difference*, Garland-Thomson arrived at the proposal for a disability cultural competency. In her 2017 article in the *Kennedy Institute of Ethics Journal*, Garland-Thomson suggests an actionable means for critical disability studies to transition from theory to practice. Like her colleagues, she identified medicine as an important locus for transition: "medical science understands us and treats us all according to its logic and practice." While Garland-Thomson recognizes this as a suitable practice for the medical field, she also asserts that

teaching disabilities studies can “enlarge our shared understanding of what it means to live with disabilities and be counted as disabled” (Garland-Thomson 2017, 325). Here, disability cultural competency

goes beyond sensitivity to language and adjustments in activities of daily living; it is developing competencies for using the world effectively, maintaining our dignity, exercising self-determination, cultivating resilience, recognizing and requesting accommodations, using accessible technology, finding community, maintaining successful relationships—all as persons living with disabilities.

Turning from a definition of cultural competency for people with disabilities, for medical professionals and the field of medicine, it is suggested that

What is needed, then, is to implement a robust disability bioethics that would translate the concept of conserving disability into a capacious yet specific set of principles, practices, policies, and competencies that can affect biomedical decision-making and life decision-making by people with disabilities. This applied disability bioethics would produce disability cultural competence for all. (Garland-Thomson 2017, 331)

Disability cultural competency demands that medical professionals see people with disabilities as more than the medical conditions listed on their charts, that their rich history and vibrant culture be seen as relevant to their experience of disability. For, “the goal of disability cultural competence would be to build an affect of pride and positive identity in people experiencing disability” (Garland-Thomson 2017, 332). When this is achieved people with disabilities will receive the respect and care they deserve both within and beyond medicine. Garland-Thomson indicates that disability cultural competency must extend to other loci, however, her project is limited to healthcare. Medical care is the primary locus of her piece because medicine typically focuses on “normalizing us and eliminating disability” and fails to “provide a context outside of medical treatment about living with disabilities” (Garland-Thomson 2017, 333).

Disability cultural competency provides a framework for educating medical professionals on the experiences of disability outside medicine, providing a more holistic understanding of the disability experience and, in turn, better equipping them to treat patients with disabilities.

Garland-Thomson analyzes structural perspectives on certain bodies that shaped the need for disability cultural competency. She suggests the early 1970s brought “new knowledge perspectives, and bodies of knowledge began to emerge, first perhaps as women’s studies, African-American studies, then as critical race theory, feminist theory, queer theory, and more recently, critical disability studies” (Garland-Thomson 2017, 323), as previously excluded bodies were increasingly included in schools. Inclusion prompted the educational system to acknowledge how it perceived and treated people of different backgrounds, cultures, and experiences. Recently, disability advocacy has challenged the medical categories assigned to people with disabilities by suggesting transitioning to a social justice framework. This framework “interprets people with disabilities as a group that has historically been denied rights and equal access to the obligations and privileges of citizenship” (Garland-Thomson 2017, 334). Encouraging greater disability cultural competency educates medical professionals about life with a disability and ultimately betters treatment of people with disabilities in all aspects of life. It also forces a recognition that most people will experience some kind of disability if they live long enough. Therefore this shift directly benefitting not just to those who currently experience disabilities, but everyone who is temporarily non-disabled. Disability cultural competency extends the conversation around disability beyond medicine and into all the spaces in which disabilities “act and are acted upon.” Despite the medical model that restrains disability to a list of medical symptoms, Garland

Thomson suggests the consideration of how disability is experienced in places like “the workplace, marketplace, domestic spaces, public spaces, and cultural spaces,”<sup>7</sup> and how that redefines the medical conception of disability (Garland-Thomson 2017, 331).

There are some critiques for the foundation of Garland-Thomson’s suggestions, namely that cultural competency discourages medical providers from thinking productively about their patients. In *Anthropology in the Clinic: The Problem of Cultural Competency and How to Fix It*, Arthur Kleinman and Peter Benson recognize that culture is “crucial to diagnosis, treatment, and care,” however, they feel it is also “important that health-care providers do not stigmatize or stereotype patients,” and they think that cultural competency does just that (Kleinman and Benson 2006, 1673-5). They argue that culture is too variable even within cultural groups because of diversity of “age cohort, gender, political association, class, religion, ethnicity, and even personality,” to be the sole guide of competency in medicine. This very variability necessitates a specific *disability* cultural competency. The diversity within cohorts of people with disabilities often overwhelms the order that functionalizes medical classifications and diagnoses. However, people with disabilities, both as a whole and in various sub-groupings,<sup>8</sup> have built vibrant cultures out of their classifications that

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<sup>7</sup> While most of the considerations for better disability cultural competency and disability inclusion focuses on physical spaces and how they can be disabling, there are other locals for evolution of inclusivity. Time has certainly been an important factor, as medical advancements have in many ways allowed for the longevity of people with disabilities lives who might previously been left to die or could not receive the appropriate medical attention because the options just did not exist. Further, technological advancements have also allowed for great inclusivity, as they have provided people with disabilities access to communication accommodations. And yet, even in an environment that is perfectly set to include someone with a disability and the social environment is aware and inclusive towards that person, certain disabilities will still present as just that, a disability. When disability is received in an environment and time of that nature, it will inform a new perspective on disability in the medical field and other professional fields as well.

<sup>8</sup> It is important to note that while people with disabilities have different lived experiences—both from disability to disability and in the spectrum of experiencing one kind of disability—not all people with

should be recognized as important to their identity. Kleinman and Benson suggest that ethnography is a better tool than culture because it “refers to an anthropologist’s description of what life is like in a ‘local world,’ a specific setting in a society” (Kleinman and Benson 2006, 1674). This is a credible critique of cultural competency, but an argument *for* disability cultural competency, which includes recognizing the diversity of disability cultural itself. Ethnography of patients with disabilities improves practitioner understanding of the lived experiences of people with disabilities that Garland-Thomson argues is so crucial to appropriate treatment of people with disabilities.<sup>9</sup>

Disability cultural competency, as Garland-Thomson proposes it, is a necessary and often missing component of medical education and practice. People with disabilities fought extensively for their rights to participate fully and equally in society; however, within the health care system, they are still reduced to a list of symptoms that disregard their lived experiences outside of medicine. Constructing disability cultural competency requires “proposing language and ways of talking about disability that are accurate yet nonprejudicial” (Garland-Thomson 2017, 333). Translating medical jargon to generally intelligible language complicates communication between patients and providers. Furthermore, the vernacular has not yet evolved to reflect society’s changing perceptions of people. A more advanced recognition of the culture and values of patients

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disabilities will even associate with the sort of cultural aspect of disability discussed in this project. Disability scholars and activists are more keenly aware of the cultural component of disability, while others live with their disability unaware or unconnected to others with similar or other disabilities at all and do not know about the disability rights movement or various advocacy efforts.

<sup>9</sup> As discussed in the previous section surveying memoirs written by parents of children with Down syndrome, these perspectives are crucial to understanding the experiences of disability language and communication. While the memoirs discussed in this project are not necessarily ethnographies of people with disabilities, they are autobiographies of people caring for people with disabilities and serve as an important tool in understanding how language effects perceptions of people with disabilities. These in conjunction with first person accounts from the person with disabilities themselves might then work towards formulating a true disability ethnography.

is “essential if practitioners are to achieve professional competence” (Harvey and Koteyko 2013, 55). In order for this to happen, there needs to be greater “awareness about, support for, development of, and promotion of disability history, culture, material culture, and arts as cultural competence” (Garland-Thomson 2017, 335).

Medical professionals should recognize the many facets of their patients and work to incorporate the experiences of their patients with disabilities as more than medical problems, but as important components of care. It is natural to implement disability cultural competency within medicine, but this is merely a first step in creating a framework to be used across disciplinary and institutional fields. Garland-Thomson succinctly remarked, “disability cultural competence is a skill set or a toolkit everyone will need to navigate life and to implement the promises and obligations of egalitarian democratic societies” (Garland-Thomson 2017, 334). Disability cultural competency is the foundation on which the following sections are built and is a crucial practice which should inform future medical education and all professional training.

### **Available Disability Cultural Competency Review**

While there is still much work to be done to develop disability cultural competency across medical education and training and to encourage its spread across other fields, there has been substantial progress in recent years. To contextualize recommendations for cross-disciplinary disability cultural competency training in the appendix of this project, I will conduct a brief review of currently available resources, materials, and trainings. The majority of these resources are for medical professionals, such as genetic counselors, specializing in genetic, prenatal, and postnatal diagnoses of disabilities. These resources have made incredible strides forward in the care and

treatment of people with disabilities within medicine and provide a framework for the following proposed educational manual.

One of the most highly regarded and widely used training options for medical professionals is through Lettercase, a part of the National Center for Prenatal and Postnatal Resources. Lettercase prepares “resources and support for medical providers and expectant parents first learning about a prenatal or postnatal diagnosis,” which detail “accurate, balanced, and up-to-date information about various genetic conditions for expectant parents first receiving the news” (“About – Lettercase” n.d.). Lettercase is affiliated with University of Kentucky’s Human Development Institute, which offers online trainings for medical professionals and advocacy organizations. The training modules focus on improving the prenatal diagnosis experience and providing accurate, up-to-date, and balanced information about genetic conditions. Training for advocacy organizations focus on community outreach, how to foster relationships with genetic counseling offices, prenatal diagnoses specifically of Down syndrome, and enhancing cultural competency. Lettercase has proven successful because they are attentive to historical narratives, evidence-based medical practice, and meaningful engagement of course students through reflective responses and interactive activities. They are well regarded by the medical community, have many professional medical partners as well as advocacy groups, and work with both the institutional fields they seek to educate and those who stand to be effected by their work. The curator of these materials, Stephanie Hall Meredith, is a rhetorician by training, a founder of the Center for Dignity in Healthcare for People with Disabilities at the University of Kentucky, and a mother of a son with Down syndrome. Inspired by her own experience receiving her son’s diagnosis,



she has devoted her career to improving the presentation of diagnostic information and parent education.

The trainings often begin with a comparison from Meredith's personal narrative. Her cousin Keith, who was painted as scary and deviant, was institutionalized and forgotten, but Meredith's son's diagnosis forced her to question what she was told about Keith. She wondered if Keith's story might have differed if he was treated as she planned to treat her son, Andy: with support and love. Utilizing narrative immerses trainees in a history that is both personal and reflective of pervasive experiences of people with disabilities in this country. This guides the conversation towards historical treatment of people with disabilities that created modern treatment frameworks. Meredith contrasts the information medical professionals provide during diagnostic consultations with various evidence demonstrating what parents actually seek in those conversations. Through this analysis, suggested frameworks are provided depending on the overarching goals of the particular module. For example, in the module titled "Brighter Tomorrows: Best Practices for Communicating a Prenatal Diagnosis of Down Syndrome," it stages interactions between a doctor and couple who became pregnant after many years of trying and then received a Down syndrome diagnosis. The video clips track conversation options, providing non-persuasive response support for providers.

Throughout each module, mandatory reflection opportunities allow participating professionals to consider the impact of their implicit biases and how to apply the training. The courses provide a historical framework to help participants contextualize suggested modifications to their practices and guide them through evidence-based explanations of suggested adjustments. Further, Meredith's experience raising a son

with Down syndrome is present throughout the coursework and engages participants personally. Interacting with a person with disabilities would create the ideal professional training, but this online series sets an effective framework for disability cultural competency education in disability diagnosis according to many who have conducted the trainings.

Operation House Call (OHC) is an organization tackling the need for interactions between medical professionals and people with disabilities. OHC was established in collaboration with The Arc of Massachusetts and several local medical and nursing schools. The goal of their programming is to bring health care professionals in training and people with disabilities and their families together to help in “building confidence, interest, and sensitivity in their work with individuals who have intellectual and or developmental differences” (“Operation House Call (OHC) About” n.d.). OHC’s training is guided by six primary learning objectives:

- Model person first behavior and understand person first thinking and language.
- Review supportive ways to deliver unexpected or difficult news to parents.
- Practice building rapport in a home visit to a family who has a family member with intellectual/developmental disability (IDD).
- Monitor personal or subjective bias that might affect an evaluation or treatment of a person with IDD.
- Demonstrate sensitivity to sibling and family issues during the family visit or in class discussion.
- Increase awareness of resources and community systems available to families.

People with disabilities make classroom visits and students make home visits to learn about the daily lived experience of those with disabilities. Since 2011, OHC has involved over 200 families of people with disabilities in the hands-on training of thousands of health care students (“Operation House Call (OHC)” n.d.). This model is

groundbreaking because it exposes students to the lives of people with disabilities outside of medicine, meaningfully teaching students disability cultural competency.

OHC also provides a variety of key resources on diversity within disability and sensitivity in interactions with patients and families of those who have disabilities. Like most available training materials, these resources focus on genetic testing and delivery of diagnoses. They expand beyond initial diagnosis to guidance on helping families adjust to life with a child who has disabilities, navigating the education system, and caring for a person with disabilities throughout their lifetime. As Garland-Thomson suggested in her proposal for disability cultural competency training, OHC also identifies language as a key component in better health care professional education. They provide resources to teach students variations in disability language, like person first versus identity first language, and encourage open conversation with patients about preferred language type. One of the first resources they offer, *Smart Doctors, Ignorant Speech*—the namesake for this very thesis—links to an article titled *Why do smart doctors use ignorant speech?* (Wallace 2013). This article cites the work of researchers who focus on disability in medical practice and offers reflection by parents on how the language their doctors used during a diagnosis affected their perspectives on their child and disability more generally. Learning these perspectives and hearing the first-hand experiences of parents of children with disabilities and people with disabilities themselves, forces students to consider the impact of their language on patients. Students learn experientially about living with a disability, rather than reading about it. Students develop the ability to empathize with the experience of disability and examine life with disabilities beyond medicine.

Reflecting on personal narratives of people with disabilities is increasingly present in education about disabilities. The Center for Disease Control and Prevention (CDC) offers an online series of personal narratives from adults with Down syndrome. Though the CDC lists Down syndrome under the problematic category of “Birth Defects,” the intentions of the personal narratives still express the value of first-person perspectives (CDC 2019). OHC takes this sort of narrative education a step further, by bringing the narratives to the classroom. Recent research points to the importance of interpersonal relationships between people with and without disabilities in building understanding and appreciation for lived experiences of those with disabilities (Weiss, Olayeye, and Tan 2017). Further, it creates the opportunity for dialogue in which people with disabilities can express their needs and descriptive language preferences. Without these personal interactions, it is difficult to break down stereotypes and impossible to make the space for patients with disabilities to express their perspectives on their own needs and care.

The National Center on Disability and Journalism (NCDJ) of the Walter Cronkite School of Journalism and Mass Communication at Arizona State University developed a substantial Disability Language Style Guide to be used by journalists. While not centered in medical field, this is an important tool that can and should be utilized in medicine. The NCDJ aims “to provide support and guidance for journalists as they cover people with disabilities” (“About NCDJ | National Center on Disability and Journalism” n.d.). The style guide was developed to assist journalists in navigating rapidly changing “language, perceptions and social mores” used to refer to people who have disabilities (“Disability Language Style Guide” 2018). The guide is introduced by Amy Silverman, an

NCDJ Board Member and author of one of the previously discussed parent memoirs. In presenting the guide, she proposes a few guidelines:

Refer to a disability only when it's relevant to the story and when the diagnosis comes from a reputable source, such as a medical professional or other licensed professional.

When possible, use people-first language unless otherwise indicated by the source.

When possible, ask the source how he or she would like to be described. If the source is not available or unable, ask a trusted family member or relevant organization that represents people with disabilities.

Avoid made-up words like "diversability" and "handicapable" unless using them in direct quotes or to refer to a movement or organization.

Silverman continues by bringing attention to the often-misplaced identification of people with disabilities as disabled when it is not relevant to the story. She asks journalists to consider whether disability is necessary to a given story before determining appropriate language. This is an important suggestion as story headlines often identify a person as disabled when it is wholly unrelated to the topic of the article, changing the story's lens. She calls on journalists to identify the subjects of their stories as people before labeling them. She closes her remarks with a straightforward request: "If you are in doubt about how to refer to a person, ask the person. And if you can't ask the person, don't avoid writing about disability. Use this guide. Do your best" ("Disability Language Style Guide" 2018).

The guide details a series of almost 200 words, discussing the background of the particular word and how to use it. Similar to the Lettercase modules, the guide discusses words in their historical and applicable medical contexts and explains how to use medicalizing and humanizing vocabulary in tandem. The entry on Down syndrome, briefly explains its medical manifestation, gives a history of its name, and discusses

associated words, both acceptable and offensive. The discussion on words associated with Down syndrome, such as *intellectually disabled*, suggests that it is “more accurate to refer specifically to Down syndrome when that is the medically diagnosed condition.” However, when talking about a person with Down syndrome outside of medical conversations, it recommends using person-first language and avoiding language such as *suffering from* or *afflicted with* because it incites a negativity. In the entry on *mental retardation*, the guide recommends using the specific disability diagnosis, and if it is unidentified, the most current, appropriate language is *a person with an intellectual disability*. It further recommends that when referring to outdated language like the word *retarded*, the word can be used as long as its context is acknowledged. This differs from some resources which refuse to say the word *retarded* in protest of its use, referring to it as *the r-word*.

There are a handful of other similar disability guides, many produced by collegiate centers for disability education or advocacy, but the JCDJ guide has some of the clearest formatting and articulation. It is unique in its reflection of journalism, which requires synchronization in quality of narrative, evidence, ethics, and rhetoric. The guide does not dictate which words are currently acceptable and unacceptable, it focuses on understanding different words’ historical and current roles. It outlines how words interact with each other and how to navigate multifaceted complexities. Though certain words are no longer appropriate, they still have a place in the historical lexicon of people with disabilities. It is not enough to say *do not use the word retard* and expect it disappear without a trace. Rather, there should be acknowledgement that certain language has been used effectively but has now become offensive, appropriately presenting the words when applicable for educational purposes. Language is the

foundation of disability cultural competency and all education on better treatment and inclusion of people with disabilities. Therefore, the JCDJ guide provides a helpful framework for navigating linguistic complexities and neatly untangles language's evolution over time.

These are just a few examples of the most successful materials and resources to guide better disability cultural competency across disciplines. Already-available, medically geared training focuses primarily on genetic counseling. Working to improve disability cultural competency where the choice to terminate a pregnancy could be impacted by misconceptions about disability is a justified first step. However, there is still significant need to further expand and develop such training across all medical education. Other medical fields may not pose the same dire outcomes as those surrounding prenatal diagnosis, but lifelong appropriate care for patients with disabilities is critical. Preconceived notions about disabilities and devaluation of the lives of people with disabilities within the medical model of disability produce poorer outcomes for patients with disabilities over time (National Council on Disability 2009). OHC's program is revolutionary because it facilitates interactions which more accurately shape student understanding of disabilities in the real world. This model can be incorporated into future expansions of disability cultural competency in medical education. Finally, language is the backbone of all conversations about disability, and rhetorical education requires more than just a list of acceptable and unacceptable words. In order for medical professionals to understand the power of their language, they must consider the history and emotion of the words they use. These resources informed the holistic disability cultural competency manual provided in the appendix.

## Conclusion

There has been much progress in the treatment and inclusion of people with disabilities, especially throughout the past few decades. While access to society has improved, conceptions about what it means to live with a disability have continued space for growth. People with disabilities themselves have initiated a change in the way they are perceived: “from individuals and their impairments to disabling environments and hostile social attitudes” (Barnes 1996, 43). Late twentieth-century movements, especially those leading up to the monumental Americans with Disabilities Act of 1990, saw a wave of self-advocates who, for the first time, were making their presence known following far too many years of oppression. However, the language often used to describe and discuss disability, particularly within medical settings, prevents the full inclusion of people with disabilities within the medical field and beyond because it forces a negative and inherently discriminatory perception of disability.

Language is paramount in shaping perception. A detailed history of the word *retard*'s transition from patient description to pejorative exemplifies a single word's ability to define how an entire class of people are viewed. Though its initiation was an innocuous attempt to aptly name a medical classification of slow development, it became a slur thrown around on the playground with ill intention. Colloquial use of the word *retard* was not encouraged to intentionally devalue those who were medically classified by such language. Rather, a word that described a trait deemed undesirable by public view was applied to any instance of unfavorable actions or objects. In this transition, those actually classified as *retarded* were cemented at the very bottom of the social hierarchy.



While the word *retard* does still surface in casual conversations, many have fought against its continued use. Changes in the use of the word *retard* in official language has initiated a monumental step forward in eliminating such offensive language in popular use. Medical classification, federal legislation, and advocacy organizations have all made the move away from language considered unanimously inappropriate. However, it is likely that future iterations of the medical language of disability will eventually become offensive and further name changes will be instituted across professional fields. Even so, the step forward in addressing this problematic language recognizes the importance of words and the desire to improve upon lessons from history. Removing the word *retard* from professional use leads the way for its decline in all spaces. The campaign to end use of the word *retard* has also heralded a new era of exposure and education about the experience of living with a disability. As such, a more truthful framework is developing to describe disability by those who experience it—both first person and from a caretaker/parental perspective. While the perspectives provided in this project did not include the voices of people with disabilities to the extent I argue they should, this is a result of the locale of the conversation being in large part at the point of diagnosis for infants. Several scholars cited throughout this project are persons with disabilities themselves and deeply informed the arguments of this project.

The example of the word *retard* is just one of many in the vast landscape of disability language. There are several instances of the manipulation of language used to define disability to incite certain perceptions of those with disabilities. While the word *retard* is a detailed example of the power of one word, in other instances language has been used on a broader scale to adjust general thinking about those with disabilities.

Within medicine, there has been much contention over the description of disability and its effects on patients themselves. During World War II, a redesign of the medical ethics curriculum taught in medical schools across Nazi occupied countries enforced a new perspective on the role of doctors and how people with disabilities were valued in society. This created an established route towards the atrocious acts of eugenics practiced on patients with disabilities at the start of the Nazi Regime. People with disabilities were already separated from society based on demoralizing views of their conditions and became targets of Nazi experiments of practices that were later used to murder millions of Jews. A shift in language and medical education made possible the murder of thousands of innocent people with disabilities who were unable to advocate for themselves. They were the victims of language that made their lives decidedly without value.

To this day, similar language is imbedded in conversations around selective abortion and physician assisted suicide, as well as the entirety of medical jargon. Medical perspectives on disability often suggest that disabilities are issues of the person that require fixing or should be eliminated altogether. There has been focus on how such language constructs prenatal diagnoses of disability. Relevant research suggests that the language used to provide a disability diagnosis is often biased against disability and impacts parents' decisions to continue or terminate the pregnancy. While there has been significant effort in providing better disability cultural competency to genetic counselors and others involved in delivering such information, training has not yet become available across all medical disciplines. Further, emerging research suggests that inadequate understanding of disability and education on how to holistically treat patients who have disabilities can lead to poorer health outcomes. Patients with

disabilities experience the same medical needs as all other people. Though sometimes they require additional medical attention due to their disabilities, they also require the same standard care as any other person. Therefore, it is important that medical providers across specialties be appropriately prepared to address patients with disabilities as people first. Antiquated views of people with disabilities being unworthy of medical care prevail. People with disabilities have fought for their right to be included, to be seen as more than just their disability. It is long overdue that this be reflected within medicine.

The attached appendix is a culmination of the research conducted for this thesis project. While it is a preliminary manual for better medical education on disability cultural competency, it is expected to be further developed beyond the degree for which this thesis is being written. The goal of the manual is to guide medical students during their education through the historical and contemporary examples that necessitate the need for such improvement in education. It is not sufficient for only fields which directly deal with conversations about disability, like genetic counseling, to receive specified training on disability; all medical professionals must receive this training. At the point in medical education where genetic counselors often receive training about disability sensitivity, the medical model of disability has already been enforced so that any education would be unlearning biases instead of forming balanced perspectives. Further, it benefits all medical students to learn about the needs of patients with disabilities, whom they will treat in any specialty they pursue, as a fundamental component of their medical degree. The manual serves as an example of what such education might look like.

Every conversation I had in preparation for and during the process of researching this project abundantly clarified the need for improvement in disability cultural competency education across medical education. The research provided in this thesis supports the importance of such education, as without it, the possibility for further misapplication of medical bias will continue to harm people with disabilities. Those with disabilities have long fought to be included in all aspects of society and are still working diligently for the future they seek. However, it will be impossible for people with disabilities to ever achieve full inclusion and respect when the very language used to describe them is inherently discriminatory. The examples provided in this project to discuss these issues are the basis for much larger rhetorical reform of disability language. While there are many loci where this is necessary, medicine is an appropriate place to start. It is within medicine that disability is first diagnosed and by that medical language the foundation for how a person with disabilities will be perceived throughout their lifetime is laid. When medical perspectives on disability shift, there will be significant change across all aspects of life for those with disabilities. Those who experience disability should not have to fight this battle alone. Every person will experience disability at some point in their life, whether permanent or temporary, congenital or mid-life, health effecting or life changing. We must all participate in this necessary change, to help those who are currently seen as medically vulnerable or insufficient and change the script around their conditions and experiences. Disability is a natural—dare I say, normal—part of every human life. We must all champion its normalization in everything we do so that those who are currently impacted by disability and the negative implications placed on them can be better welcomed and included in society. Words are powerful; we must use them wisely.

## Bibliography

- “Abortion: The Hidden Holocaust.” n.d. [Www.Abortionfacts.Com](http://www.Abortionfacts.Com). Accessed June 11, 2020. <https://www.abortionfacts.com/literature/abortion-the-hidden-holocaust>.
- “About – Lettercase.” n.d. [Lettercase.Org](http://Lettercase.Org). Accessed June 24, 2020. <https://www.lettercase.org/about/>.
- “About NCDJ | National Center on Disability and Journalism.” n.d. National Center on Disability and Journalism. Accessed June 24, 2020. <https://ncdj.org/about/>.
- “About Spread the Word.” 2019. Spread the Word. February 7, 2019. <https://www.spreadtheword.global/about>.
- “About The Arc of the United States.” 2019. The Arc. 2019. <https://thearc.org/about-us/>.
- “Actions Speak Louder Than Words: Origin and Meaning.” n.d. [Www.Bloomsbury-International.Com](http://Www.Bloomsbury-International.Com). <https://www.bloomsbury-international.com/student-ezone/idiom-of-the-week/1589-actions-speak-louder-than-words/>.
- Adams, Rachel. 2014. *Raising Henry : A Memoir of Motherhood, Disability, and Discovery*. Yale University Press.
- Aerts, Jon. 2010. “Mikulski Joins Inspiration for Rosa’s Law at White House Signing Ceremony.” CNS Maryland. CNS Maryland. October 8, 2010. <https://cnsmaryland.org/2010/10/08/mikulski-joins-inspiration-for-rosas-law-at-white-house-signing-ceremony/>.
- Allan, Julie. 2015. “Inclusion as an Ethical Project.” In *Foucault and the Government of Disability*, 281–97. Ann Arbor, MI: University of Michigan Press.
- Allen, Barry. 2015. “Foucault’s Nominalism.” In *Foucault and the Government of Disability*, 93–107. Ann Arbor, MI: University of Michigan Press.

- American Psychiatry Association. 2013. "Intellectual Disability." *Psychiatry.Com*, 2013.
- Anderson, Carolyn Anne. 2015. "Real and Ideal Spaces of Disability in American Stadiums and Arenas." In *Foucault and the Government of Disability*, 245–60. Ann Arbor, MI: University of Michigan Press.
- Andrews, Erin E. 2020. *Disability as Diversity : Developing Cultural Competence*. New York, Ny: Oxford University Press.
- Aristotle, and George A Kennedy. 2007. *On Rhetoric : A Theory of Civic Discourse*. New York: Oxford University Press.
- Asch, Adrienne. 1991. "PrenatalDiagnosis and Selective Abortion: A Challenge to Practice and Policy." *American Journal of Public Health* 89 (11): 1649–57.
- Associated Press. 2009. "Biden Attends Special Olympics, Awards Medals | The Spokesman-Review." *Www.Spokesman.Com*. February 13, 2009. <https://www.spokesman.com/stories/2009/feb/13/biden-attends-special-olympics-awards-medals/>.
- Baker, Dana Lee. 2017a. *Disability and U.S. Politics : Participation, Policy, and Controversy*. Santa Barbara, California: Praeger, An Imprint Of Abc-Clio, Llc.
- Baker, Dana Lee. 2017b. *Disability and U.S. Politics: Participation, Policy, and Controversy*. ABC-CLIO.
- Barnes, Colin. 1996. "Theories of Disability and the Origins of the Oppression of Disabled People in Western Society." In *Disability and Society: Emerging Issues and Insights*. London: Longman.
- Barry, Dan. 2016. "Giving a Name, and Dignity, to a Disability." *The New York Times*, May 7, 2016. <https://www.nytimes.com/2016/05/08/sunday-review/giving-a-name-and-dignity-to-a-disability.html>.

- Beirne-Smith, Mary, James R Patton, and Shannon H Kim. 2006. *Mental Retardation : An Introduction to Intellectual Disabilities*. Upper Saddle River, N.J.: Pearson Merrill Prentice Hall.
- “Benjamin Rush.” 2014. Biography.Com. April 2, 2014.  
<https://www.biography.com/political-figure/benjamin-rush>.
- Bérubé, Michael. 1998. *Life as We Know It : A Father, a Family, and an Exceptional Child*. New York: Vintage Books.
- Bérubé, Michael. 2017. *Life as Jamie Knows It : An Exceptional Child Grows Up*. Boston: Beacon Press.
- Bickenbach, Jerome E. 2012. *Ethics, Law, and Policy*. Thousand Oaks, Calif: Sage.
- Bromage, D I. 2006. “Prenatal Diagnosis and Selective Abortion: A Result of the Cultural Turn?” *Medical Humanities* 32 (1): 38–42.  
<https://doi.org/10.1136/jmh.2004.000208>.
- Bruns, Florian, and Tessa Chelouche. 2017. “Lectures on Inhumanity: Teaching Medical Ethics in German Medical Schools Under Nazism.” *Annals of Internal Medicine* 166 (8). <https://doi.org/10.7326/m16-2758>.
- Butler, F.O. 1945. “A Quarter of a Century’s Experience in Sterilization of Mental Defectives in California.” *American Journal Mental Deficiency* 49 (4).  
[http://www.eugenicsarchive.org/eugenics/image\\_header.pl?id=1384&printable=1&detailed=0](http://www.eugenicsarchive.org/eugenics/image_header.pl?id=1384&printable=1&detailed=0).
- Carlson, Laura M., and Neeta L. Vora. 2017. “Prenatal Diagnosis.” *Obstetrics and Gynecology Clinics of North America* 44 (2): 245–56.  
<https://doi.org/10.1016/j.ogc.2017.02.004>.
- Carlson, Licia. 2015. “Docile Bodies, Docile Minds: Foucauldian Reflections on Mental

- Retardation.” In *Foucault and the Government of Disability*, 133–52. Ann Arbor, MI: University of Michigan Press.
- Carroll, Lewis. 1872. *Through the Looking Glass*. Raleigh, NC: Hayes Barton Press.
- CDC. 2019. “Real Stories: Living with Down Syndrome | CDC.” Centers for Disease Control and Prevention. October 2, 2019.  
<https://www.cdc.gov/ncbddd/birthdefects/stories/downsyndrome.html>.
- Chan, Fong, Norman L Berven, and Kenneth R. 2004. *Counseling Theories and Techniques for Rehabilitation Health Professionals*. New York: Springer.
- Charlton, James I. 1998. *Nothing about Us without Us : Disability Oppression and Empowerment*. Berkeley: University Of California Press.
- Cherney, James L. 2019. *Ableist Rhetoric : How We Know, Value, and See Disability*. University Park, Pennsylvania: The Pennsylvania State University Press.
- Cook, John. 2001. “The ‘R’ Word.” *Slate Magazine*. July 6, 2001.  
<https://slate.com/human-interest/2001/07/the-r-word.html>.
- Cossey, Dilys. 1998. “Campaigning for Abortion Law Reform.” *Abortion Law and Politics Today*, 20–26. [https://doi.org/10.1007/978-1-349-26876-4\\_3](https://doi.org/10.1007/978-1-349-26876-4_3).
- Costello, Victoria. 2012. *A Lethal Inheritance: A Mother Uncovers the Science behind Three Generations of Mental Illness*. Prometheus.
- Croom, Adam M. 2011. “Slurs.” *Language Sciences* 33 (3): 343–58.  
<https://doi.org/10.1016/j.langsci.2010.11.005>.
- Davis, Lennard J. 1995. *Enforcing Normalcy : Disability, Deafness, and the Body*. New York: Verso.
- Davis, Lennard J. 2013. *The End of Normal : Identity in a Biocultural Era*. Ann Arbor, Mich.: Univ. Of Michigan Press.



- Davis, Lennard J. 2017. *The Disability Studies Reader*. New York, Ny: Routledge, An Imprint Of The Taylor & Francis Group.
- “Definition of RETARD.” n.d. Www.Merriam-Webster.Com. Accessed February 19, 2020. <https://www.merriam-webster.com/dictionary/retard#h2>.
- “Definition of Retard | Dictionary.Com.” n.d. Www.Dictionary.Com. Accessed February 19, 2020. <https://www.dictionary.com/browse/retard>.
- “Definition of Retard by Oxford Dictionary.” n.d. Lexico Dictionaries | English. Accessed September 2, 2020. <https://www.lexico.com/en/definition/retard>.
- “Definition of RETARDED.” n.d. Www.Merriam-Webster.Com. Accessed February 19, 2020. <https://www.merriam-webster.com/dictionary/retarded#h1>.
- “Disability Language Style Guide.” 2018. Ncdj.Org. National Center on Disability and Journalism. 2018. <https://ncdj.org/style-guide/>.
- Dolmage, Jay. 2014. *Disability Rhetoric*. Syracuse, New York: Syracuse University Press.
- Dolmage, Jay. 2016. *Disability Rhetoric*. Syracuse University Press.
- Downes, Lawrence. 2013. “Opinion | A Word Gone Wrong.” *The New York Times*, March 2, 2013, sec. Opinion. <https://www.nytimes.com/2013/03/03/opinion/sunday/a-word-gone-wrong.html>.
- Dunne, Madeleine. 2020. “Why I’m Dropping ‘Stupid’ and ‘Idiot’ from My Vocabulary.” Medium. February 21, 2020. <https://medium.com/@kohlgrrl/why-im-dropping-stupid-and-idiot-from-my-vocabulary-66c432dd8733>.
- Dworetz, April. 2014. “Disability Ethics in Neonatology: A New Script for Neonatologists

- Informing Parents About Their Infant with Down Syndrome.” Thesis, James T. Laney School of Graduate Studies of Emory University.
- Dwyer, Devin. 2010. “Rahm Emanuel ‘Retarded’ Comment Puts Offensiveness in Spotlight.” ABC News. February 3, 2010. <https://abcnews.go.com/WN/rahm-emanuel-retarded-comment-puts-offensiveness-spotlight/story?id=9738134>.
- Estreich, George. 2013. *Shape of the Eye : A Memoir*. Penguin Books.
- Faden, R R, A J Chwalow, K Quaid, G A Chase, C Lopes, C O Leonard, and N A Holtzman. 1987. “Prenatal Screening and Pregnant Women’s Attitudes toward the Abortion of Defective Fetuses.” *American Journal of Public Health* 77 (3): 288–90. <https://doi.org/10.2105/ajph.77.3.288>.
- Fairman, Christopher M. 2010a. “The Case against Banning the Word ‘Retard.’” *Www.Washingtonpost.Com*, February 14, 2010. <https://www.washingtonpost.com/wp-dyn/content/article/2010/02/11/AR2010021103896.html>.
- Fairman, Christopher M. 2010b. “Outlook: The Case against Banning the Word ‘Retard.’” *Www.Washingtonpost.Com*, February 16, 2010. <https://www.washingtonpost.com/wp-dyn/content/discussion/2010/02/12/DI2010021204001.html>.
- Fine, Michelle, and Adrienne Asch. 1988a. *Women with Disabilities: Essays in Psychology, Culture, and Politics*. Temple University Press.
- Fine, Michelle, and Adrienne Asch. 1988b. “Disability Beyond Stigma: Social Interaction, Discrimination, and Activism.” *Journal of Social Issues* 44 (1): 3–21. <https://doi.org/10.1111/j.1540-4560.1988.tb02045.x>.
- Fiona Kumari Campbell, and Palgrave Macmillan. 2012. *Contours of Ableism : The*

- Production of Disability and Abledness*. New York: Palgrave Macmillan.
- Foucault, Michel. 1997. "On the Genealogy of Ethics: An Overview of Work in Progress." In *The Essential Works of Michel Foucault, 1954-1948*, edited by Paul Rabinow. New York: New Press.
- Fox, Dov, and Christopher L. Griffin. 2009. "Disability-Selective Abortion and the Americans with Disabilities Act." Papers.Ssrn.Com. Rochester, NY. November 20, 2009. <https://ssrn.com/abstract=1362146>.
- "Frequently Asked Questions about the R-Word." 2019. Spread the Word. January 30, 2019. <https://www.spreadtheword.global/resource-archive/r-word-faq>.
- Friedman, Carli. 2016. "Outdated Language: Use of 'Mental Retardation' in Medicaid HCBS Waivers Post-Rosa's Law." *Intellectual and Developmental Disabilities* 54 (5): 342–53. <https://doi.org/10.1352/1934-9556-54.5.342>.
- Fries, Kenny. 2019. "How Everyday Language Harms People with Disabilities." Medium. January 8, 2019. <https://howwegettonext.com/how-everyday-language-harms-people-with-disabilities-f22d8d62b51>.
- Garland-Thomson, Rosemarie. 2017. "Disability Bioethics: From Theory to Practice." *Kennedy Institute of Ethics Journal* 27 (2): 323–39. <https://doi.org/10.1353/ken.2017.0020>.
- Garland-Thomson, Rosemarie. 2019. "A Cross-Cultural Neuroethics View on the Language of Disability." *AJOB Neuroscience* 10 (2): 91–92. <https://doi.org/10.1080/21507740.2019.1618411>.
- Garland-Thomson, Rosemarie. 2020. "How We Got to CRISPR: The Dilemma of Being Human." *Perspectives in Biology and Medicine* 63 (1): 28–43. <https://doi.org/10.1353/pbm.2020.0002>.

- Giancgreco, Michael F., and Kevin Ruelle. 2002. *Path for People with Special Needs Clears the Path for Everyone! Peytral Publications Inc.*
- Gillam, L. 1999. "Prenatal Diagnosis and Discrimination against the Disabled." *Journal of Medical Ethics* 25 (2): 163–71. <https://doi.org/10.1136/jme.25.2.163>.
- Goddard, Henry Herbert. 1939. *The Kallikak Family : A Study in the Heredity of Feeble-Mindedness*. New York: Macmillan.
- Gopnik, Adam. 2020. "Revisiting Mengele's Malignant 'Race Science.'" *New York Magazine*, June 15, 2020.  
<https://www.newyorker.com/magazine/2020/06/22/revisiting-mengeles-malignant-race-science>.
- Harvey, Kevin, and Nelya Koteyko. 2013. *Exploring Health Communication : Language in Action*. Milton Park, Abingdon, Oxon ; New York: Routledge.
- "History of DSM." n.d. Tpb.Psy.Ohio-State.Edu. Accessed February 17, 2020.  
<https://tpb.psy.ohio-state.edu/5681/notes/dsm/01.htm>.
- "History of Stigmatizing Names for Intellectual Disabilities Continued." n.d. MentalHelp.Net. Accessed February 17, 2020.  
<https://www.mentalhelp.net/intellectual-disabilities/history-of-stigmatizing-names-for-intellectual-disabilities-continued/>.
- Hodges, Rick. 2019. "The Rise and Fall of 'Mentally Retarded.'" Medium. July 4, 2019.  
<https://medium.com/s/story/the-rise-and-fall-of-mentally-retarded-e3b9eea23018>.
- Hudson, Cindy. 2013. "Interview with George Estreich, Author of *The Shape of the Eye*."

- BookClub.Com. May 3, 2013.  
<http://motherdaughterbookclub.com/2013/05/interview-with-george-estreich-author-of-the-shape-of-the-eye/>.
- Hughes, Bill. 2015. "What Can a Foucauldian Analysis Contribute to Disability Theory?" In *Foucault and the Government of Disability*, 78–92. Ann Arbor, MI: University of Michigan Press.
- Janvier, Annie, and Andrew Watkins. 2013. "Medical Interventions for Children with Trisomy 13 and Trisomy 18: What Is the Value of a Short Disabled Life?" *Acta Paediatrica* 102 (12): 1112–17. <https://doi.org/10.1111/apa.12424>.
- Jarman, Michelle, Leila Frances Monaghan, and Alison Quaggin Harkin. 2017. *Barriers and Belonging : Personal Narratives of Disability*. Philadelphia: Temple University Press.
- Johanson-Sebera, Brandy, and Julia Wilkins. n.d. "The Uses and Implications of the Term 'Retarded' on YouTube." Accessed May 24, 2020.  
<https://scholarspace.manoa.hawaii.edu/bitstream/10125/58467/491.pdf>.
- Keyword, Kirsty, and Margaret Flynn. 2019. "Healthcare Decision-Making By Adults with Intellectual Disabilities: Some Levers To Changing Practice."  
Intellectualdisability.Info. 2019. <http://www.intellectualdisability.info/historic-articles/articles/healthcare-decision-making-by-adults-with-intellectual-disabilities-some-levers-to-changing-practice>.
- Kleinman, Arthur, and Peter Benson. 2006. "Anthropology in the Clinic: The Problem of Cultural Competency and How to Fix It." *PLoS Medicine* 3 (10): e294.  
<https://doi.org/10.1371/journal.pmed.0030294>.
- Kumari Campbell, Fiona. 2015. "Legislating Disability, Negative Ontologies and the

- Government of Legal Identities.” In *Foucault and the Government of Disability*, 108–30. Ann Arbor, MI: University of Michigan Press.
- Lyle, Monique L., and Stacy Clifford Simplican. 2015. “Elite Repudiation of the R-Word and Public Opinion About Intellectual Disability.” *Intellectual and Developmental Disabilities* 53 (3): 211–27. <https://doi.org/10.1352/1934-9556-53.3.211>.
- Makofsky, Serena. 2014. “History of the ‘R’ Word & States That Still Use It.” Special Education Guide. March 7, 2014. <https://www.specialeducationguide.com/blog/the-r-word-a-history-of-the-term-which-states-still-use-it/>.
- Margrit Shildrick. 2009. *Dangerous Discourses of Disability, Subjectivity and Sexuality*. Basingstoke: Palgrave Macmillan.
- McBryde Johnson, Harriet. 2003. “Unspeakable Conversations.” *The New York Times*, February 16, 2003. <https://www.nytimes.com/2003/02/16/magazine/unspeakable-conversations.html>.
- McCammon, Sarah. 2017. “NPR Choice Page.” Npr.Org. January 17, 2017. <https://www.npr.org/sections/thetwo-way/2017/01/17/509734620/u-s-abortion-rate-falls-to-lowest-level-since-roe-v-wade>.
- McGuire, Anne. 2015. “‘life Worth Defending’ Biopolitical Frames of Terror in the War on Autism.” In *Foucault and the Government of Disability*, 350–71. Ann Arbor, MI: University of Michigan Press.
- Metzl, Jonathan M., and Helena Hansen. 2014. “Structural Competency: Theorizing a

- New Medical Engagement with Stigma and Inequality.” *Social Science & Medicine* 103 (February): 126–33.  
<https://doi.org/10.1016/j.socscimed.2013.06.032>.
- Mikulski, Barbara. 2010. *Rosa’s Law*. GovTrack.com.  
<https://www.govtrack.us/congress/bills/111/s2781/text>.
- Myser, Catherine. 2003. “Differences from Somewhere: The Normativity of Whiteness in Bioethics in the United States.” *The American Journal of Bioethics* 3 (2): 1–11.  
<https://doi.org/10.1162/152651603766436072>.
- National Council on Disability. 2009. “The Current State of Health Care for People with Disabilities.” Washington, D.C.: National Council on Disability.
- National Council on Disability. 2019. “Quality-Adjusted Life Years and the Devaluation of Life with Disability.” Washington D.C.: National Council on Disability.
- Nilika Mehrotra. 2013. *Disability, Gender and State Policy : Exploring Margins*. Jaipur: Rawat Publications.
- “Nuremberg Code.” 2018. Ushmm.Org. United States Holocaust Memorial Museum. 2018. <https://www.ushmm.org/information/exhibitions/online-exhibitions/special-focus/doctors-trial/nuremberg-code>.
- Obama, Barack. 2010. “Remarks by the President at the Signing of the 21st Century Communications and Video Accessibility Act of 2010.” presented at the Signing of Rosa’s Law, October 8.
- “Operation House Call (OHC).” n.d. The Arc of Massachusetts. Accessed June 24, 2020. <https://thearcofmass.org/ohc>.
- “Operation House Call (OHC) About.” n.d. Operation House Call. Accessed June 24, 2020. <https://www.operationhousecall.com>.

- Parens, Erik, and Adrienne Asch. 1999. "Special Supplement: The Disability Rights Critique of Prenatal Genetic Testing Reflections and Recommendations." *The Hastings Center Report* 29 (5): 1–22. <https://doi.org/10.2307/3527746>.
- Parens, Erik, and Adrienne Asch. 2003. "Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations." *Mental Retardation and Developmental Disabilities Research Reviews* 9 (1): 40–47. <https://doi.org/10.1002/mrdd.10056>.
- Patterson, Orlando. 2020. "The Long Reach of Racism in the U.S." *Wall Street Journal*, June 5, 2020, sec. Life. <https://www.wsj.com/articles/the-long-reach-of-racism-in-the-u-s-11591372542>.
- Peters, Mark. 2017. "The R-Word and the Challenging History of Words for Dummies." BostonGlobe.Com. March 6, 2017. <https://www.bostonglobe.com/ideas/2017/03/06/the-word-and-challenging-history-words-for-dummies/6heGdgEkMRaUw4MPYVF6yN/story.html>.
- Petersen, Emily E., Nicole L. Davis, David Goodman, Shanna Cox, Carla Syverson, Kristi Seed, Carrie Shapiro-Mendoza, William M. Callaghan, and Wanda Barfield. 2019. "Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007–2016." *MMWR. Morbidity and Mortality Weekly Report* 68 (35): 762–65. <https://doi.org/10.15585/mmwr.mm6835a3>.
- Rapp, Christof. 2010. "Aristotle's Rhetoric (Stanford Encyclopedia of Philosophy)." Stanford.Edu. 2010. <https://plato.stanford.edu/entries/aristotle-rhetoric/>.
- "Retard, Verb." n.d. [Www.Oxfordlearnersdictionaries.Com](http://www.oxfordlearnersdictionaries.com). Accessed February 19, 2020. [https://www.oxfordlearnersdictionaries.com/us/definition/english/retard\\_1](https://www.oxfordlearnersdictionaries.com/us/definition/english/retard_1).



- Robey, Kenneth L., Linda Beckley, and Matthew Kirschner. 2006. "Implicit Infantilizing Attitudes About Disability." *Journal of Developmental and Physical Disabilities* 18 (4): 441–53. <https://doi.org/10.1007/s10882-006-9027-3>.
- Rochman, Bonnie. 2017. *The Gene Machine : How Genetic Technologies Are Changing the Way We Have Kids--and the Kids We Have*. New York: Scientific American / Farrar, Straus And Giroux.
- "Rosa's Law (2010 - S. 2781)." n.d. GovTrack.Us. Accessed May 24, 2020. <https://www.govtrack.us/congress/bills/111/s2781>.
- Rubens Figueroa, Jesús de, Blanca del Pozzo Magaña, José L. Pablos Hach, Claudia Calderón Jiménez, and Rocío Castrejón Urbina. 2003. "Heart Malformations in Children With Down Syndrome." *Revista Española de Cardiología (English Edition)* 56 (9): 894–899. <https://www.revespcardiol.org/en-heart-malformations-in-children-with-articulo-13051768>.
- Rush, Benjamin. 1805. *Medical Inquiries and Observations: In Four Volumes*. Philadelphia, PA: Conrad.
- Sandel, Michael J. 2009. *The Case against Perfection : Ethics in the Age of Genetic Engineering*. Cambridge, Mass.: Belknap Press.
- Saxton, Marsha. 2017. "Disability Rights and Selective Abortion." In *The Disability Studies Reader*, 87–99. Routledge, an Imprint of the Taylor & Francis Group.
- Schmidt, Ulf. 2008. *Karl Brandt : The Nazi Doctor : Medicine and Power in the Third Reich*. London: Hambledon Continuum.
- Shapiro, Joseph. 2018. "For Some With Intellectual Disabilities, Ending Abuse Starts

- With Sex Ed.” Npr.Org. January 9, 2018.  
<https://www.npr.org/2018/01/09/572929725/for-some-with-intellectual-disabilities-ending-abuse-starts-with-sex-ed>.
- Shields, Christopher. 2015. “Aristotle (Stanford Encyclopedia of Philosophy).”  
Stanford.Edu. 2015. <https://plato.stanford.edu/entries/aristotle/>.
- Shriver, Timothy. 2010. “The Bigotry behind the Word  
‘Retard.’” *Www.Washingtonpost.Com*, February 15, 2010.  
<https://www.washingtonpost.com/wp-dyn/content/article/2010/02/14/AR2010021402893.html>.
- Silverman, Amy. 2016. *My Heart Can't Even Believe It*. Bethesda, MD: Woodbine House.
- Simi Linton. 1998. *Claiming Disability : Knowledge and Identity*. New York: New York University Press.
- Skotko, Brian G., Priya S. Kishnani, and George T. Capone. 2009. “Prenatal Diagnosis of Down Syndrome: How Best to Deliver the News.” *American Journal of Medical Genetics Part A* 149A (11): 2361–67. <https://doi.org/10.1002/ajmg.a.33082>.
- Soldatic, Karen, and Kelley Johnson. 2020. *Global Perspectives on Disability Activism and Advocacy : Our Way*. London ; New York Routledge, Taylor Et Francis Group.
- “Spread the Word to End the Word Pledge.” 2020. Special Olympics Rhode Island. 2020.
- Sue, Derald, Allen Ivy, and Paul Pederson. 1996. “A Theory of Multicultural Counseling and Therapy.”
- Sue, Stanley. 2006. “Cultural Competency: From Philosophy to Research and

- Practice.” *Journal of Community Psychology* 34 (2): 237–45.  
<https://doi.org/10.1002/jcop.20095>.
- Taylor, Ashley. 2015. “Expressions of ‘Lives Worth Living’ and Their Foreclosure through Philosophical Theorizing on Moral Status and Intellectual Disability.” In *Foucault and the Government of Disability*, 372–95. Ann Arbor, MI: University of Michigan Press.
- “The Right to Self-Determination: Freedom from Involuntary Sterilization.” 2014. Disability Justice. 2014. <https://disabilityjustice.org/right-to-self-determination-freedom-from-involuntary-sterilization/>.
- Tremain, Shelley. 2015. *Foucault and the Government of Disability*. Ann Arbor, Mich.: Univ. Of Michigan Press.
- Trent, James W. 1995. *Inventing the Feeble Mind : A History of Mental Retardation in the United States*. Berkeley: University Of California Press.
- US. 2018. “Nearly 1 in 5 People Have a Disability in the U.S., Census Bureau Reports – Miscellaneous - Newsroom - U.S. Census Bureau.” Census.Gov. 2018.  
<https://www.census.gov/newsroom/releases/archives/miscellaneous/cb12-134.html>.
- Wakeman, Jessica. 2016. “Abortion and Down Syndrome.” Healthline. December 6, 2016. <https://www.healthline.com/health-news/the-debate-over-terminating-down-syndrome-pregnancies#1>.
- Waldschmidt, Anne. 2015. “Who Is Normal? Who Is Deviant? ‘Normality’ and ‘Risk’ in Genetic Diagnostic and Counseling.” In *Foucault and the Government of Disability*, 191–207. Ann Arbor, MI: University of Michigan Press.
- Wallace, Maureen. 2013. “Held to a Higher Standard?” SheKnows. April 17, 2013.

<https://www.sheknows.com/parenting/articles/987815/doctors-should-use-people-first-language/>.

Wallsten, Peter. 2010. "Chief of Staff Draws Fire From Left as Obama Falters." *Wall Street Journal*, January 26, 2010, sec. US.

<https://www.wsj.com/articles/SB10001424052748703808904575025030384695158>.

Weiss, Sierra. 2015. *Talking to the Doctor*. Boston, MA: Massachusetts General Hospital Down Syndrome Clinic.

<https://www.massgeneral.org/assets/MGH/pdf/children/down-syndrome-talking-to-the-doctor.pdf>.

Weiss, Sierra. 2017. "Where Do Holocaust Euthanasia Practices Fit into the Modern Euthanasia Discussion?" *Researchers of Emory* (blog). October 13, 2017.

<http://researchersofemory.blogspot.com/2017/10/where-do-holocaust-euthanasia-practices.html>.

Weiss, Sierra, Tara Olayeye, and Jit Tan. 2017. "What Can Be Learned From Relationships Between People With and Without Disabilities: Inter-abled Relationships – Journal of Humanities in Rehabilitation." *Journal of Humanities in Rehabilitation*. 2017. <https://www.jhrehab.org/2017/10/17/what-can-be-learned-from-relationships-between-people-with-and-without-disabilities-inter-abled-relationships/>.

"What Is Rhetoric?" n.d. Department of Rhetoric and Writing Studies. San Diego State University. [https://rhetoric.sdsu.edu/resources/what\\_is\\_rhetoric.htm](https://rhetoric.sdsu.edu/resources/what_is_rhetoric.htm).

Wilson, James C, and Cynthia Lewiecki-Wilson. 2001. *Embodied Rhetorics : Disability in Language and Culture*. Carbondale: Southern Illinois University Press.

Yates, Scott. 2015. "Truth, Power, and Ethics in Care Services for People with Learning Difficulties." In *Foucault and the Government of Disability*, 65–92. Ann Arbor, MI: University of Michigan Press.

## Appendix

# Disability Cultural Competency

Constructing Bioethical Disability Rhetoric in Medicine

By

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A thesis submitted to the Faculty of the  
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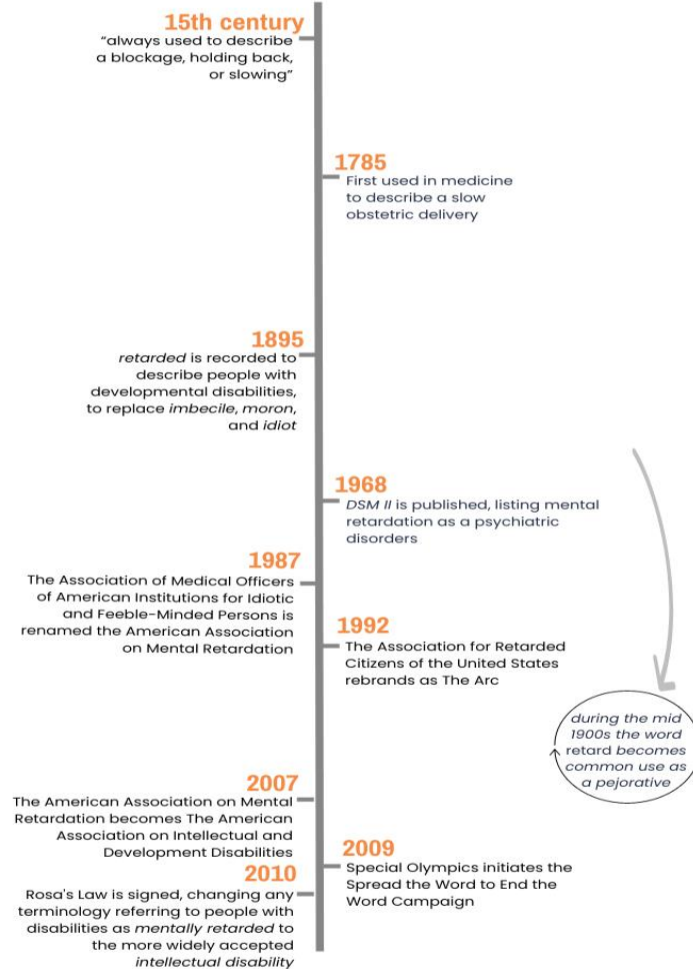
{ The words we use carry important weight and the words of a medical professional are of particular importance. Every word has a history and a historical context. Make sure you understand the words that you use and that they carry the message you intend. }

## EDUCATIONAL MANUAL CONTENT

- 1 History of the Word *Retard*
- 2 Eugenics: Then and Now
- 3 Smart Doctors, Ignorant Language

## HISTORY OF THE WORD *RETARD*

Throughout history there have been a variety of words to describe people with disabilities, many of them eventually making the transition from a medical description or classification to a pejorative. *Imbecile*, *moron*, *idiot*, and many others all originated as words to describe intellectual disability. The word *retard* in particular has proven important to the fight for disability rights and equality as it exemplifies the hurt a single word can cause and the stereotypes it can enforce.

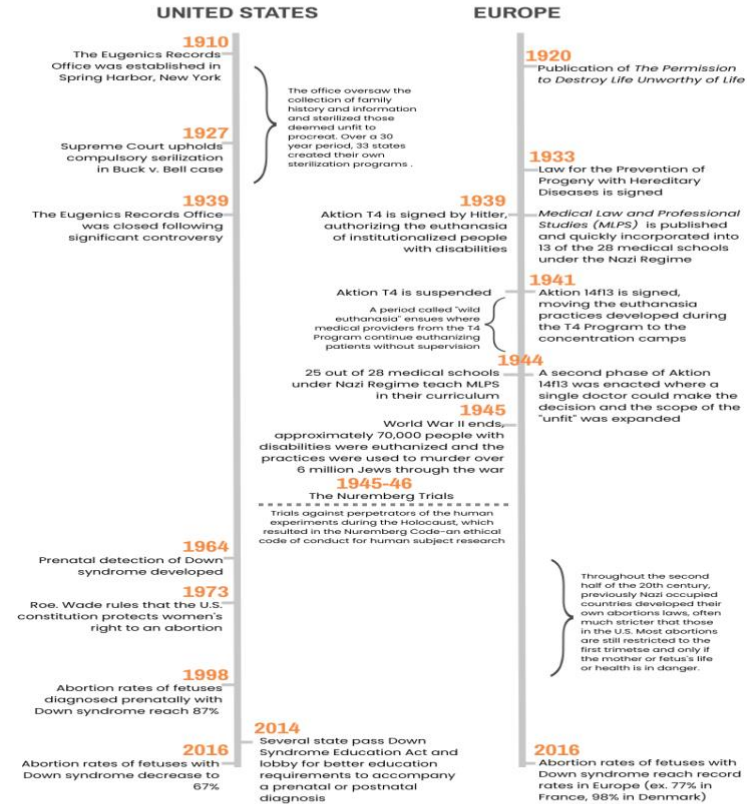


## LESSONS FROM THE WORD *RETARD*

- Words mean more than just their intended description
- Words can change in appropriateness over time

# EUGENICS OF PEOPLE WITH DISABILITIES IN MEDICAL PRACTICE: THEN AND NOW

At the end of the 19th century, several prominent statisticians applied the concepts of their field to the development of a system of norming the population. They divided the human population into the ideal norm, and all those who did not fit within that norm—mainly people with disabilities. This concept is now known as eugenics.



During the Holocaust, the Nazis used language such as "sub-human," "parasites," and "mass" to describe Jews. The killing of Jews was considered an "evacuation" of a problem, and torture was understood as "medical research." Language used to justify abortion follows a similar pattern. Unborn fetuses are often considered to be "sub-human" and are referred to as a "mass of tissue." The removal of a fetus is sometimes also referred to as an "evacuation" of the fetus from the womb.



## LESSONS FROM THE WORD *EUGENICS*

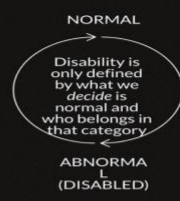
- Words pave the way for actions
- Words can effect perceptions of the object of their description
- Medical professionals should use their words thoughtful consideration



# SMART DOCTORS, IGNORANT LANGUAGE

People with disabilities make up 19% of the U.S. population

- People with disabilities often have additional medical needs associated with their condition
- It is very likely that in your practice you will have at least one patient, if not several, who have disabilities that you know how to appropriately address them and their disability



## MODELS OF DISABILITY

- MEDICAL MODEL** Disability is a problem with an individual that requires medical intervention to be cured or fixed.
- SOCIAL MODEL** Disability is a product of socially constructed norms and physical expressions of those norms.

## PEOPLE WITH DISABILITIES ARE PEOPLE FIRST

Patients with disabilities should not be reduced to a list of their medical symptoms.

They should be recognized as having vibrant lives beyond their medical experiences.

Not sure how to refer to someone's disability?

- ? wheelchair user
- ? confined to a wheelchair
- ? suffering from paralysis
- ? experiencing paralysis
- ? paralyzed

Just ask! I'm a person who experiences paralysis and uses a wheelchair.

It is better that you ask than assume and refer to me incorrectly.

It is best to refer to people with disabilities in the language that they identify with. People with different disabilities have different preferences (person first language or disability identity). Avoid using negative words like "suffering" or "afflicted with."

Do not assume that a patient is unable to participate in a conversation about their own health.

How are you feeling today? Is there anything you want to discuss? Would you like me to be involved in the conversation?

how old are you? I'm 9 -  
- what grade are you in? I'm in school -  
- She learns one-on-one with a teacher at her school -  
- but what grade is she in?

Patients with disabilities will not always fit into all the boxes on the checklist because the "typical" questions are designed for the "normal" patient.

Listen to what your patient or their family is telling you and be accommodating to their experiences. Do not try to confine people with disabilities to the expectations of "normalcy."

## LISTEN TO YOUR PATIENTS, DO NOT MAKE ASSUMPTIONS

**ASK**

Ask what disability terminology they prefer.

**TALK**

Talk about disability and how it impacts your patient

**LISTEN**

Respect your patients with disabilities as people first.

Sustain dignity. Respect self determination. Cultivate resilience. Recognize and request. Use accessible technologies. Support community building. Maintain successful relationships.