THE IMPACT OF ABLEIST PERCEPTIONS IN THE PRENATAL GENETIC TESTING PROCESS

By

ALYSSA LAURIANNA VINCENZ

A thesis submitted to W.A Franke Honors College

In partial fulfillment of the requirements for a Bachelor's Degree with Honors in Biology

THE UNIVERSITY OF ARIZONA

MAY 2 0 2 3

Approved by:

Dr. Angel Pimentel

Department of Molecular and Cellular Biology

ABSTRACT

With the rapid advancement of genetics, prenatal genetic testing has become a mainstream process within prenatal care. Prenatal genetic testing aims to be a non mandatory process that allows for premature detection of genetic abnormalities including autosomal chromosome aneuploidies, sex chromosome aneuploidies, copy number variants, microdeletions, and polymorphisms that ideally allow for prospective parents to be more informed about the genetic condition of the fetus, allowing for better reproductive choice and more informed decision making on how to proceed with the pregnancy. Aside from the common ethical concerns, how the discrimination against the disability community impacts the prenatal genetic testing process is largely unacknowledged. Ableism is deep-rooted in society, and related discriminatory ideas have been perpetuated by society. The in utero identification of potential disabilities can be negatively influenced by inaccurate disability stereotypes, causing both medical professionals and patients involved to perceive a disabled fetus as tragic, worthless, and incapable of a fulfilling life. Powerful health organizations often exhibit ableism through their missions to reduce and eliminate disability, and efforts to eliminate entire communities of particular disabilities identifiable via genetic testing have already commenced. This thesis aims to provide a comprehensive analysis of how ableist perceptions in prenatal genetic testing have the potential to eliminate certain disabilities from birth, to spread false information regarding quality of life of a disabled person, to repeat harmful themes of eugenics from the past, and to validate the obvious disability discrimination within the medical field that leads to massive health disparities. In order to proceed with prenatal genetic testing appropriately, the medical field must recognize and resolve disability related health disparities, integrate the social model of disability, develop confidence in accurately characterizing disability and treating patients with

disabilities, and improve availability of genetic services and educational communication with patients. Further investigation of ableism within the prenatal genetic testing process through guided research could better identify how to restrict the damaging repercussions of disability discrimination within the prenatal genetic testing process.

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PREFACE

The ethicality of abortion is not meant to be debated within this thesis whatsoever. Furthermore, this thesis is not based upon the argument if selective abortion is ethically acceptable. I fully support the decisions of any pregnant person and how they decide to proceed with their pregnancy, as they should have the right to an abortion. Abortion as a personal choice based upon life circumstances and selective abortion due to prenatal genetic testing have different motives. Generalized abortion aims to terminate pregnancy based on the pregnant person not wishing to have a child at that time due to a multitude of factors, while selective abortion based on prenatal genetic testing results may warrant pregnancy termination solely due to the recognition of specific traits deemed undesirable and disabled. This paper aims to only evaluate how prenatal genetic testing (PGT) may exceed its non-malicious purposes and influence major decisions, such as an elective abortion, solely based upon the presence of a possible disability or impairment in the fetus. Additionally abortion under any circumstances is now illegal in many states, therefore investigation of how ableism influences prenatal genetic testing is extremely relevant as the options are more limited, possibly putting additional strain onto expecting parents. I also want to recognize that some genetic diseases that can be diagnosed through this process will ultimately be fatal regardless of the amount of possible resources available, and eliminating ableist perceptions from the process will not yield different outcomes for the fetus. Recognizing ableist perceptions in the prenatal genetic testing process can lead to better patient care, as individuals can be authentically educated about a possible life of their fetus with a disability. Generally speaking, I will investigate how PGT can be negatively influenced by the public's ableist views if there remains a high prevalence of ableism, a lack of informed consent, and a lack of thorough counseling. Despite my criticism of the prenatal genetic testing

process I do absolutely recognize how the process is beneficial and imperative for many patients and healthcare professionals. Additionally, I do recognize that plenty of disabilities do not arise from a predisposed genetic factor, and I will focus upon the disabilities identifiable via genetic testing. Recognizing and discussing the oppression the disability community faces even before birth can help demonstrate the significant discrimination that comes from society and is unacknowledged.

I am a nondisabled individual, but I aim to advocate for the disability community with pure intent. The desired result of this thesis is to help identify how ableist ideas reinforced by society influence nondisabled individuals in the prenatal genetic testing process in a negative manner. I aim to help recognize the ableist actions completed by individuals involved in the prenatal genetic testing process. When attempting to minimize ableism, it is fundamental to first recognize ableist actions and preconceptions, whether purposeful or not. I do not intend to speak on behalf of the disability community, as I myself have not experienced disability discrimination and every person with disabilities has a different experience both with their disability and within society. Additionally, my choice of vocabulary aims to reference the disability community in a respectful manner, however members of the disability community may prefer certain language and vocabulary that are not used within this literature. I will aim to use person-first language, placing emphasis on the individuals rather than the presence of a disability.

INTRODUCTION

Problem Background

America has a long history of trying to eradicate undesirable heritable characteristics, and themes of this may have been passed on into the prenatal genetic testing process further fueled by ableism. The eugenics movement started in the early 1900's when the American Breeder's Association was created, having a subset of goals created by Davenport promoting positive eugenics emphasizing "restricting the reproduction of the genetically unfit and the elimination of undesirable traits" (Kimmelman, p.187). While the definitions of genetically unfit and undesirable are vague, stereotypes can be implied, meaning that irregularities in genetic DNA, functioning, or physical presence resulting in a disability can be deemed as unappealing and avoidable through eugenic mechanisms. The eugenics movement was very influential in America, and this movement emphasized bettering the human race. The eugenics movement proceeded with goals to eliminate the undesirable, promoting ableist ideals through the process and labeling this movement as bettering the human race through eradication of the disabled (Carlow, 2019). Since the American eugenics movement, the American Breeder's association has been reinstated as the American Genetic Association, which maintains a huge importance in the genetic and genomic fields today (Kimmelman, 1983). Part of the most recent mission statement established by the American Genetic Association (n.d.) states, "we are committed to accomplishing this mission with the most inclusive group of members and contributors possible, unrestricted by race, gender, sexuality, religion, political affiliation, or background". Unfortunately, like many other large and powerful health organizations today, the disability community is not referenced within their mission statements although nearly all other minorities are. The U.S. Department of Health and Human Services from the National Institutes of Health

(2017) directly defines their mission as “to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability”. This organization, with a 45 billion dollar budget, explicitly makes a mission out of gaining knowledge to help eliminate disability in America. Planned Parenthood’s (n.d.) mission statement is to “help people live full, healthy lives — no matter your income, insurance, gender identity, sexual orientation, race, or immigration status”. Planned Parenthood is highly involved in the prenatal care of thousands of pregnancies nationwide, prenatal genetic testing included, however they too disregard the disability community within their mission statement.

These are only small examples of how the disability, despite being the most prevalent minority, is frequently overlooked in missions aiming for inclusion and equality. It is possible that the field of prenatal genetic testing can enhance the rejection of the disability community. The Centers for Disease Control and Prevention (2019) directly describes birth defects as “common, costly, and critical”, which is solely referencing disabilities as imperfections and emphasizing how detrimental and economically draining these disabilities are. This statement shows how massive health organizations that aim to cure various diseases obtain a commercialized view of disability with a goal of eliminating disability in an attempt to preserve finances and resources. In order for the prenatal genetic testing process to be informative regarding genetic abnormalities and disabilities in a constructive manner, it is imperative to recognize the ableist presumptions that exist both within the medical field and society.

Problem Statement

Ableist perceptions are socially constructed and ingrained within our society. DUe to eugenics remaining as a trending topic, considering the possibility of ableist themes within the field of prenatal genetic testing is extremely relevant. Prenatal genetic testing will only become more popular due the increased accuracy, a wider range of testing, and the overall increasingly less invasive and less costly experience. A serious evaluation of how the societal construction of ableism affects the decision making process of prenatal genetic testing is needed to help limit discrimination and depreciatory attitudes towards the disability community throughout such personal and intimate situations. Ethical evaluation related to disability in the prenatal genetic testing process has been deprived. Identification of disability discrimination in the prenatal genetic testing process should stimulate the healthcare community to be aware of ableism and to help put an end to unethical perception of disability.

LITERATURE REVIEW

1. PRENATAL GENETIC TESTING

Purpose and Methodology of Prenatal Genetic Testing

Prenatal genetic testing is a rapidly evolving practice in the medical field. According to Jelin et al. (2019), the goal of prenatal genetic testing is "to identify as many pregnancies as possible at high risk for abnormal outcomes while simultaneously providing reassurance to women carrying typical pregnancies". Birth defects among other significant congenital abnormalities are not infrequent. It is estimated that significant congenital abnormalities, most suspected to be genetic in nature, occur in 3% of live births, not including the amount of spontaneous miscarriages caused by significant chromosomal abnormalities (Minear et al., p.370, 2015). In efforts to reduce detrimental consequences of some genetic abnormalities, prenatal genetic testing has surfaced and increased in popularity. The genetic testing process is completely optional and personal choice, but often completed as many parents-to-be find the process reassuring and allowing for forethought. The decision to complete the prenatal genetic testing process is a very significant decision in pregnancy. Dr. O'Brien (2020) suggests that when deciding whether to undergo prenatal genetic testing, patients should evaluate what their risk factors are, how much they would want to know, and what they would do with that information. There are two parts within the prenatal genetic testing process. First, prenatal genetic screening will be completed. Results of this screening are in the form of risk factors, therefore if abnormal results are found the testing will proceed into prenatal diagnostic testing.

Prenatal genetic screening will be performed through noninvasive measures. As of 2022 according to Gordan and Langaker, the primary categories of prenatal genetic testing include "ultrasonography, maternal carrier status of specific genetic disorders, maternal serum assays

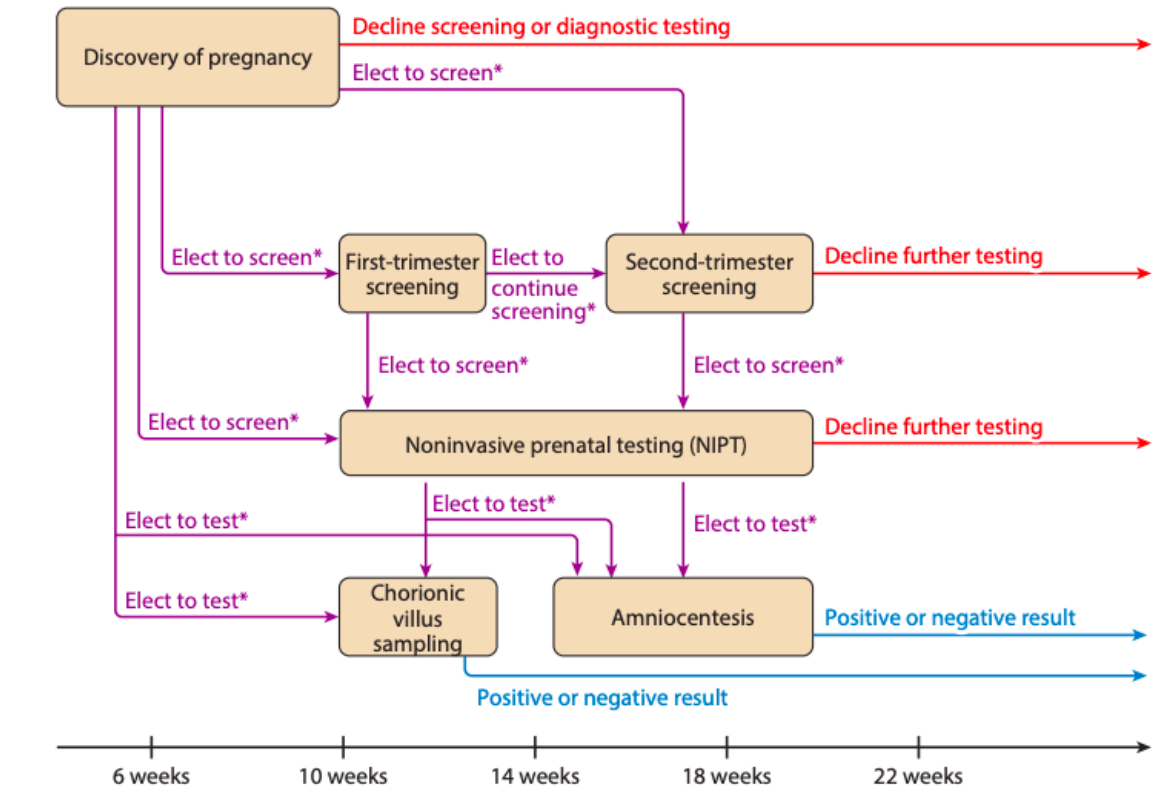
aiming to detect aneuploidy, and maternal plasma fetal cell-free fetal DNA (cffDNA), which has been used for aneuploidy, microdeletion, and copy number variants (CNVs)". Ultrasonography is the typical imaging one would expect when pregnant. The purpose of this is to monitor the anatomical structures of the unborn fetus through a noninvasive, painless process. Irregularities in body, organs, heart, vessel structures are possible to be detected depending on the development of the fetus at the time of the ultrasound. A recently new method is nuchal translucency sonograms where enlarged nuchal translucency can be detected, and this is often indicative of aneuploidies or other adverse pregnancy outcomes (Bilardo et al.). Maternal carrier status testing for specific genetic disorders can be done at any time before and during pregnancy and is completed by simple blood draws. Mutations and allele types will be detected through this, which can predict the probability of the fetus being affected by the genetic diseases of concern. Diseases that are frequently recommended to be tested for using this method include spinal muscular atrophy, cystic fibrosis, hemoglobinopathies, fragile X syndrome, and Tay-Sachs (American College of Obstetricians and Gynecologists' Committee on Genetics, 2017). Maternal serum assays are capable of detecting chromosomal abnormalities. According to the Victorian Clinical Genetics Services Prenatal Testing Team (2021), conditions evaluated for include Down syndrome, Edwards syndrome, Patau syndrome, and neural tube conditions. Cell free fetal DNA is free floating fetal DNA that exists within the maternal circulation. This test is completed through a simple blood draw from the mother. The goal of prenatal genetic screening is to identify risks for major chromosomal disorders, mainly including trisomies that cause Down syndrome, Edwards syndrome, Patau syndrome, but also sex chromosome disorders ("Prenatal Cell-Free DNA Screening", 2021).

Positive results for the prenatal screening tests explained above are not an official confirmation for the presence of the disease, for they are only an identification of abnormal risk factors for various genetic diseases. Diagnostic testing will be completed using methods of amniocentesis and chorionic villus sampling (CVS) to confirm genetic disease within the fetus. Prenatal genetic diagnostic methods were available prior to prenatal genetic screening that is less invasive and more accessible. Prenatal testing originally gained popularity in the 1970s with the goal of evaluating fetal genetic information in high risk pregnancies via invasive chorionic villus sampling or amniocentesis (Pös et al., 2019). CVS samples placental cells via biopsy of placental tissue containing the same genetic material as the fetus, and amniocentesis is the sampling of the amniotic fluid surrounding the fetus and containing loose fetal tissue (Centers for Disease Control and Prevention, 1995). These diagnostic tests officially confirm the presence of a detectable genetic disorder. It is important to note that there is only a limited amount of genetic diseases that can be tested for. There are a vast quantity of genetic diseases and disorders that cannot be detected through the prenatal testing process, however scientific advancement is likely to keep extending the amount of testable genetic diseases.

Due to the methodology, prenatal genetic screening (PGS) poses no risk for the pregnancy since results are typically attained through a simple blood drawing from the mother or an ultrasound. Constrastingly prenatal diagnostic testing poses a risk to both the infant and mother, but the risk is not striking. A study done by Nanal et al. (2003) found that CVS procedure-related loss of pregnancy was only 0.23%, and amniocentesis procedure-related loss of pregnancy was 0.7%. The risk of miscarriage is present, but is remarkably small and prenatal diagnostic testing is often warranted due to maternal request, higher maternal age, history of previous pregnancy complications, and abnormal prenatal genetic screening results. Some

patients may opt out of prenatal diagnostic testing due to this risk even if they have pregnancy risk factors or positive prenatal screening results. **Figure 1** displays a timeline of the prenatal genetic testing process, demonstrating where patients may opt for further testing or decline further testing. The decision to proceed with prenatal diagnostic testing is entirely the patient's choice.

Figure 1



This figure displays the typical progression of testing within the prenatal genetic testing process along a weeks gestation timeline, exhibiting the limited amount of time patients have to make significant testing decisions within their pregnancy. © 2015. From "Noninvasive Prenatal

Genetic Testing: Current and Emerging Ethical, Legal, and Social Issues" by Minear, M., Alexis, S., Allyse, M., Michie, M., & Chandrasekharan, S., 2015, *Annu Rev Genomics Hum Genet, 16*(1), 369-398. This figure is included on the basis of fair use.

Role of Medical Professionals in the Prenatal Genetic Testing Process

Prenatal genetic testing is electively completed through a patient's obstetrician. Obstetric (OB) health care providers typically make regular contact with a pregnant patient both throughout the pregnancy and after, therefore these providers hold a position of power as patients depend on them to track the health of both themselves and their fetus. Due to this, health care providers obtain great responsibility when explaining the concept and process of prenatal genetic testing. OB providers are all responsible for proposing the option of prenatal genetic testing with adequate guidance, counseling, and explanation. According to Collicchia et al. (2016), the American College of Obstetricians and Gynecologists providers should directly communicate the following with the patient:

> "(1) detection and false-positive rates, (2) advantages, disadvantages and limitations of the screening tests, and (3) the option of diagnostic testing. Counseling should be nondirective, with the goal of allowing the patient to make an informed choice to pursue noninvasive screening, invasive testing, or no testing".

This statement accurately describes precautionary measures that are supposed to be in place in order for parents-to-be to make an educated decision that they are well informed upon and prepared for. A study of 210 patients aimed to discover if these guidelines were followed by medical professionals, and results found 78% of women chose to complete genetic screening, but the majority of providers did not act in accordance with guidelines recommended by the

American College of Obstetricians and Gynecologists and lacked thorough discussion about the prenatal genetic screening (PGS) process (Collicchia et al., 2016). This study should pose concern, for typically the majority of pregnant women are offered the option of PGS. When this offer is presented, it is the responsibility of the OB provider to properly explain the purpose and process of prenatal genetic testing from an unbiased perspective. It is important for patients not be pressured into completion of the PGS. Feeling of pressure to complete prenatal genetic testing may arise secondary to limited personal knowledge on the subject making them feel obligated to complete testing if they believe it is a requirement to ensure the health of the fetus. This would not fall under informed consent and could add additional fearfulness during pregnancy.

In order to ensure patients are continuously well informed, OB providers should be completely confident in their ability to guide the patient before, during, and after the prenatal genetic testing. A study consisting of 216 surveys completed by OB professionals identified barriers to effective patient counseling and demonstrated limited confidence of OB professionals in patient-valued topics (Farrell et al., 2015). This illustrates a major problem affecting the prenatal genetic testing process. If the providers themselves are uncertain in their own abilities to communicate with patients, patients are likely receiving a lesser standard of care in this process. A combination of limited confidence in counseling for PGS and inadequate discussion with patients does not offer comprehensive understanding within the prenatal genetic testing process. This may result in providers pressuring the testing with lack of thorough explanation, and patients accepting the testing without being adequately knowledgeable about what prenatal genetic testing could reveal.

In attempts to offer a more comprehensive understanding of prenatal genetic testing, genetic counseling is expected to be involved if prenatal genetic screening yields increased risk

for genetic diseases or if prenatal diagnostic testing confirms genetic disorders. According to Devers et al. (2013), the National Society of Genetic Counselors strongly advocates for "informed consent, education, and counseling by a qualified provider, such as a certified genetic counselor" when considering prenatal genetic testing. Considering this recommendation, it is important to note genetic counseling is not required upon completion of prenatal genetic testing. Since genetic counseling is not mandated, a lack of understanding of the genetic testing process may persist if OB providers fail to meet the expectations previously discussed and genetic counselors are not utilized. It is important to note that patients may still lack informed decision making even if having been to genetic counseling. As seen in a study done by Browner et al. (2003), patients who lack a background of genetic testing experience various methods of miscommunication within genetic consultation which can contribute to further misunderstanding. Genetic counseling may sway patients into participating in the process due to emphasis on genetic anomalies being aversive and undesirable. Communicating how atypical genetic patterns may present themselves in the fetus in the form of a disability should be done sensitively and conscientiously. Both OB providers and genetic counselors withhold major power and influence in patient decision making while completing prenatal genetic testing, so it is essential that these medical providers properly act within their scope of practice.

Possible Courses of Action Based Upon Prenatal Genetic Testing Results

If pregnant patients choose to undergo prenatal genetic testing, they will be alerted of any abnormal results indicating higher risk for genetic anomalies. Patients may opt for prenatal genetic testing to allow for confidence in knowing what to expect and to have the ability to plan. Patients often opt out of PGT if they prefer anonymity and feel as if the results of the testing

would not impact their continuation of pregnancy. Many patients prefer gaining as much knowledge of what to expect as possible, and prenatal genetic testing gives the opportunity for parents to educate themselves upon the genetic disorder, which can lead to a more informed decision on how to proceed. Medical professionals, either an OB provider or genetic counselor, can explain to patients how the genetic disease can impact the fetus both in utero and after birth. Furthermore, patients and medical professionals can select medical care in advance to best prepare for birth if necessary, allowing for better prepared medical care throughout the pregnancy and at birth. Patients exhibit their own personal choices based upon the results of prenatal genetic testing, whether they only completed PGS, or completed both PGS and diagnostic testing. Options concluding PGT include adoption, termination of the pregnancy based upon location, or carrying the fetus to term. Continuation of the pregnancy will include integrative management such as producing birth plans and providing emotional support. Termination of the pregnancy can be done via selective abortion. The effects of Roe v. Wade being overturned will heavily influence the decision making process status post positive prenatal diagnostic testing. The laws for abortion vary in each state based upon gestational age, fetal abnormality, events of rape or incest, and threatening health problems to the mother. It is even more important now to provide interdisciplinary support to patients expecting a fetus with genetic abnormalities, as many would have chosen selective abortion but are currently unable to based upon state laws. Due to gestational age restrictions, the prenatal genetic testing often must be done as early in the pregnancy as possible. Patients may only have access to primary screenings that are not diagnostic, and positive screening results can influence patients to select abortion despite the lack of official confirmation of abnormality via diagnostic testing (Raymond et al., 2022). Every patient should have access to all steps of prenatal genetic testing if desired,

yet gestational age restricted abortion influences patients to speed up the process and to make less informed decisions regarding the health of their fetus due to fear of abortion inaccessibility later on in pregnancy. Just as the overturn of Roe v. Wade limits abortion, it may indirectly affect access to prenatal genetic testing. Patients who wish to undergo prenatal genetic testing to ensure health of the fetus and themselves may be influenced to terminate the pregnancy as a result even if it is illegal in their state, but this problematic as states will have evidence of PGT and may prosecute those who seek abortion outside of state borders (Allyse & Michie, 2022). Patients and medical professionals should remodel the progression of the typical prenatal genetic testing process according to state abortion laws, but this may lead to further ethical challenges and health disparities.

Socioeconomic Aspects of Prenatal Genetic Testing

Many services of the medical field are not provided uniformly to the entire population, especially in the US. Adequate health care, including prenatal care, is dependent upon a patient's health insurance, social history, and socioeconomic status. The implications varying socioeconomic factors have on the prenatal genetic testing process is pertinent as patient background can influence their level of informed consent, their access to prenatal testing, and their decision making process. A study done based upon a self-administered questionnaire completed by recent postpartum patients found a pronounced relationship between the sufficiency of generalized prenatal care and factors including education, income, and occupation (Donabedian and Rosenfeld, 1961). Underserved communities, often with lower education and income, are more likely to face additional barriers and inconsistencies within the prenatal care process. This may yield less access to prenatal genetic testing, particularly since the genetic

testing process is a relatively new technological process that can be difficult to interpret and can be expensive depending on health insurance quality. A study done by Kuppermann et al. (2014) involving women with varying levels of education and literacy, found that those who had access to an interactive-decision support system that was free of cost were less likely to participate in prenatal genetic testing and exhibited higher levels of knowledge regarding aspects of the process. This demonstrated how an accentuating explanation behind the motives of prenatal genetic testing along with eliminating economic burden of the process can allow for women to be more informed about their choices in prenatal genetic testing.

When discussing the financial burden involved with PGT, the pricing heavily fluctuates depending upon the specificity and intensity of testing, the state of residence, and the health insurance carrier. A routine health coverage used by millions is Medicaid. According to Ranji et al. (2022), most Medicaid responding states cover 1st trimester prenatal screening (38 of 40), all responding states cover amniocentesis, most responding states cover CVS (39 of 42), and most responding states cover genetic counseling (32 of 42) which is especially relevant considering Medicaid covers “four of 10 births nationally”. According to this study, many patients covered by Medicaid should likely receive coverage for all portions of the prenatal genetic testing process, however those who are not eligible for Medicaid may not receive similar coverage. Eligibility for healthcare coverage of prenatal genetic testing also fluctuates depending on if the testing is medically necessary, determined by pregnancy history, age, family history, and other relevant circumstances. Health insurance companies have the ability to approve what is appropriate for coverage, and without coverage prices range vastly.

Socioeconomic status not only just impacts the accessibility and affordability of prenatal genetic testing, but it also influences the decision making process after the testing is completed.

Abortion access depending on the state and county will vary, prohibiting many pregnant patients from having the decision to terminate the pregnancy. It is important in this case the patients are fully informed upon what the prenatal genetic testing may conclude, and how the patients can be properly guided on how to continue with the pregnancy and birth. On the other hand, people of high socioeconomic status may have access to abortion care by personal connection and through traveling. Patients who plan to continue the pregnancy with integrative management may have varying experiences. Patients with low socioeconomic status may not be able to access genetic counseling, have a lesser quality of generalized prenatal care, and be unable to make arrangements with specialists to create a high quality birth plan. Patients with higher socioeconomic status may receive better prenatal care and create a high quality birth plan that can translate into a better state of health of the fetus and better generalized management of the genetic abnormality.

Beneficial Qualities of Prenatal Genetic Testing

Due to the increasing prevalence of the prenatal genetic testing, it is reasonable to acknowledge the valuable features it offers to expecting parents, medical professionals, and public health in general ahead of exploring possible unfavorable qualities. While the quantity of genetic abnormalities that can be detected via prenatal genetic testing is continuously expanding, the genetic diseases that can be detected currently are typically very severe and require extensive treatment. These genetic diseases that can be detected may require large financial demands, massive responsibility from the family involved, and allocation of many particular resources from medical facilities involved. According to Peach and Hopkin (2007), prenatal genetic testing offers insight to short term and long term outcomes of genetic disease, allows for prenatal

planning, and helps identify treatment options. Identifying the expectations during pregnancy can both enhance reproductive choice and provide opportunities for advanced planning. Depending on the state laws in which the pregnant patient resides, the pregnant patient will have the option to terminate the pregnancy if the diagnosis of the fetus appears to be unmanageable based upon her current means. If the pregnant patient chooses to continue the pregnancy, advanced planning based upon the prenatal genetic testing is available. Advanced planning between medical professionals and expecting parents may include a birth plan, selection of a certain hospital, and setting up proper medical equipment and resources prior to the birth. Prenatal genetic testing is also beneficial when considering the increasing maternal age. Munne et al. (1995) found that aneuploidy increases with maternal age. According to March of Dimes (n.d.), from 2018-2020 44.4% of live births were women ages 30-39 and 12.8% of births were women 40 and older. As the prevalence of geriatric pregnancy increases, there will be higher incidences of genetic disease related to aged embryos. Prenatal genetic testing is a method of precaution when recognizing how increasing maternal age is associated with increased risk pregnancy complications, such as the detectable chromosomal aneuploidies. It is important to note that although investigation of how advanced maternal age (AMA) contributes to gene abnormalities remains very limited, it is established that AMA is associated with heightened risk of chromosomal abnormalities, Down's syndrome, and autism spectrum disorders (Correa-de-Araujo and Yoon, 2021).

Outside of these beneficial qualities of PGT, some individuals may argue that PGT is valuable since it yields the opportunity to intercept the birth of a fetus with a genetic disease ultimately preventing reprehensible outcomes if the fetus would have been born. Generally the boundaries between the advantages and disadvantages remain undefined as the process within itself comes with variable circumstances that provide contrasting arguments.

Common Ethical Arguments Regarding Prenatal Genetic Testing

Modification of embryos with goals of improving preferable traits is not a new ethical argument. Prenatal genetic testing has the ability to identify genetic anomalies that have been historically labeled as undesirable, explaining its frequent ethical debate. The process has rapidly gained popularity due to its abilities to conveniently identify significant genetic irregularities very early in pregnancy, allowing for selection of preparatory measures through a pregnancy. The prenatal genetic testing process can be extremely impactful for decision making during pregnancy, hence there are many identified systematic issues with prenatal genetic testing.

Reproductive autonomy may be difficult to fully maintain during the prenatal genetic testing process secondary to the sparsity of genetic counseling availability and minimal understanding of the field of genetics by patients, furthermore globalization and standardization of the process may hinder the non obligatory feature of prenatal genetic testing (Allyse et al., 2015). Reproductive autonomy in this case refers to the patient being educated to an extent that offers an in-depth understanding of this medical process, and for the patient to be able to make uninfluenced and independent decisions regarding their body through the process. Unfortunately this standard is often not met, initiating concern in this process as decisions may be swayed by medical professionals providing biased or limited perspectives on aspects of the process. Global access and standardization of PGT has been of ethical concern due to poor patient education and unequal access. Many lower income countries do not have access to the opportunity of PGT despite having increased rates of some genetic diseases in their populations. Even if the opportunity for prenatal genetic testing were available, other forms of prenatal care including formation of a birth plan, abortion, and genetic counseling may be out of reach. Interpretation

and communication of the purpose of PGT and courses of action after testing may significantly vary between countries. Patients in some portions of the world may have little to no knowledge of PGT and its purpose. Other areas may highlight PGT as a way of eliminating disability in an attempt to form a stronger society.

It is apparent that the beneficiaries of prenatal genetic testing are a topic of debate. Prenatal testing aims to screen and diagnose genetic disorders or anomalies while in utero in an attempt to permit educated decision making in progressing through pregnancy. The goal should be to better the health and quality of life for the fetus, not to be a convenience factor for parents or medical professionals. One possible argument is described by Malinowski (1994), “prenatal genetic screening is presently a tool for prospective parents, not their fetuses”. It is important that parents are not completing the prenatal genetic testing to avoid a fetus with genetic disorders for their convenience, however an argument against this can also be made for parents having the right to decide for themselves what they are capable of supporting and caring for. Prenatal genetic testing does not have the ability to prevent the genetic anomalies, for it can only identify what anomalies are present and exert influence on how expecting parents will continue with the pregnancy. A survey of human genome research experts done by Ekberg (2007) aimed to explain that prenatal genetic testing does not object to rid of the disabled, but instead aims to eliminate disability, and even with the possible elimination of disability through genetics, disability will continue the populations due to other avenues such as injury or infectious disease. The ethical argument focused upon in this thesis will be how the prenatal genetic testing process can be influenced by discriminative perceptions regarding disability.

2. ABLEISM

Defining Ableism

As defined by Ladau (2021, p. 70), “ableism is attitudes, actions, and circumstances that devalue people because they are disabled or perceived as having a disability”. Ableism is a form of ubiquitous discrimination that is just as relevant and prevalent as racism and sexism. It aims to draw separation and create a power imbalance between those with disabilities and those without disabilities. This portrays that society’s definition of a “normal” individual, or one without disabilities, is somehow superior to an individual with a disability. Secondary to this, just as there is male privilege and white privilege, there is able privilege. Able privilege can be defined as having unearned advantages in various aspects of life primarily due to the absence of a disability. It is crucial for nondisabled people to recognize this privilege. This can warrant further investigation of how society is always convenient for them but is frequently inaccessible and inconvenient to people with disabilities. A continuous struggle related to ableism is simply defining what a disability is. Contrary to popular belief, the disability experience is not an unvaried experience, and it is heavily impacted by medical, social, and environmental factors. Disability is part of an individual’s identity and obtains its own culture. Disability is not simply an unfortunate quality of a human being. If people continue to hold incorrect definitions of disability, ableism will continue leading challenges in obtaining equal rights and accessibilities for the disability community.

Brief History of Ableism and Disability Rights

Ableism is a deep rooted phenomenon in human history. Ancient ableist beliefs were rooted in ideas that disability is divine punishment, a mythological monstrosity, a form of

comical entertainment, or a manifestation of evil, leading to society commiting acts of infanticide, forced sterilization, and slavery towards individuals with disabilities (Bringnell, 2008). Society continued to reinforce disability discrimination over time as disabled people were sent off to institutions and asylums with dreadful conditions. The disability community was continuously viewed as uneconomical and inefficacious, further enhancing their segregation and detestation from society. In the last century, advocating for disability greatly intensified and given more recognition due to great quantities of disabled veterans after the World Wars. Achieving disability rights in law was a long process. The first disability civil rights law, section 504 of the Rehabilitation act, was passed in 1973 and aimed to eliminate disability discrimination within federally funded programs ("Section 504 of the Rehabilitation Act, n.d.). This allowed further progression of disability rights to the Americans with Disabilities Act. The ADA is described as an "equal opportunity" law that aims to prohibit discrimination towards disabled people by providing the accommodations needed for them to function as a conventional member of society ("Introduction to the ADA", n.d.). Although the law aims to provide equal opportunity to the disability community, an abundance of barriers persist secondary not only due to ableism but also due to the failure to implicate the social model of disability.

Models of Disability

It is a long standing belief that disability is undesirable due to the presence of an impairment causing limitations in one's ability. Ableism feeds into this belief, illustrating disability as something that needs to be fixed in order to regain ability. This is partially due to the utilization of the medical model of disability, rather than the social model. The medical model accentuates the idea that disability is an adverse impairment that requires fixing. The fault is

placed on the person with a disability, implying that resolving the disability will lead to a more fulfilling life. Disability Nottinghamshire (2011) describes the medical model as looking at "what is wrong with the person and not what the person needs", contributing to lessened independence of people and construing the idea that disabled people should be held to lower expectations. Medical providers favor this model, as their medical and physiological background interprets disability as the problem factor, and they aim to best eliminate and correct the impairment as they would for other illnesses and diseases. This is not always helpful to the person with the disability, as their disability may be unrelated to their current complaints and administration of medical treatment would not fix the problems they are experiencing. Medical professionals do not see having disability as a major part of someone's identity, culture, and life, and instead see disability as the personal obstructive factor. This interpretation contributes to ableism, as the person with a disability is seen as defective in some way and the able body is interpreted as innately superior (Guevara, 2021). Ultimately the medical model indirectly implies that disability equates to a lesser quality of life instead of investigating how the construction of disability by society withholds disabled people from equal opportunities. Better utilization of the social model of disability could lead to more equitable opportunities for the disability community. The basis of the social model is recognizing how the construction of society itself was made for nondisabled people without regard to people with disabilities, therefore disabled people face many more undeserved disadvantages. The social model values personal experience and acknowledges that society's organization makes a person disabled due to the barriers they have to face (Disability Nottinghamshire, 2011). In this model, society has the power to adapt and provide better accessibility for the disability community, resulting in equal opportunities between disabled and nondisabled individuals. Disability is a socially constructed phenomenon

and with proper accommodation a disabled person will not be limited in society. The strict utilization of only the medical model of disability by medical professionals creates a strong one sided narrative. This narrative is projected onto patients, where they can be led to believe a disabled body is defective and requires treatment. In the prenatal genetic testing process, the medical model of disability will immediately identify abnormal results as an unfortunate problem that reflects a defective fetus. Some genetic anomalies detected in the prenatal genetic testing process may be fatal and tragic, but some genetic abnormalities may reflect a less critical disability where the quality of life can be improved by an accommodating society using the social model.

3. THE RELATION BETWEEN PRENATAL GENETIC TESTING AND ABLEISM

An important part of the ableism definition when relating prenatal genetic testing to ableism is how individuals are devalued due to them having been perceived as having a disability. The prenatal genetic testing process is evaluating for physical differences via ultrasound and for genetic anomalies typically indicative of genetic diseases. There are limitations to determining the severity of the suspected disease or disability in utero, therefore only perceptions of how the disease or disability influence the decision making process. Just the perception, or the impression that someone has a disability, yields discrimination in society. This represents just how much society, not the disability itself, is the limiting factor in the lives of many people with disabilities. The disability experience of a disease is not completely consistent between individuals, nor can anticipated perceptions about a condition accurately portray a disability experience every time. In order to reduce the impact of ableism in prenatal genetic testing it is crucial to first identify how disability can be a lived experience of an individual, not

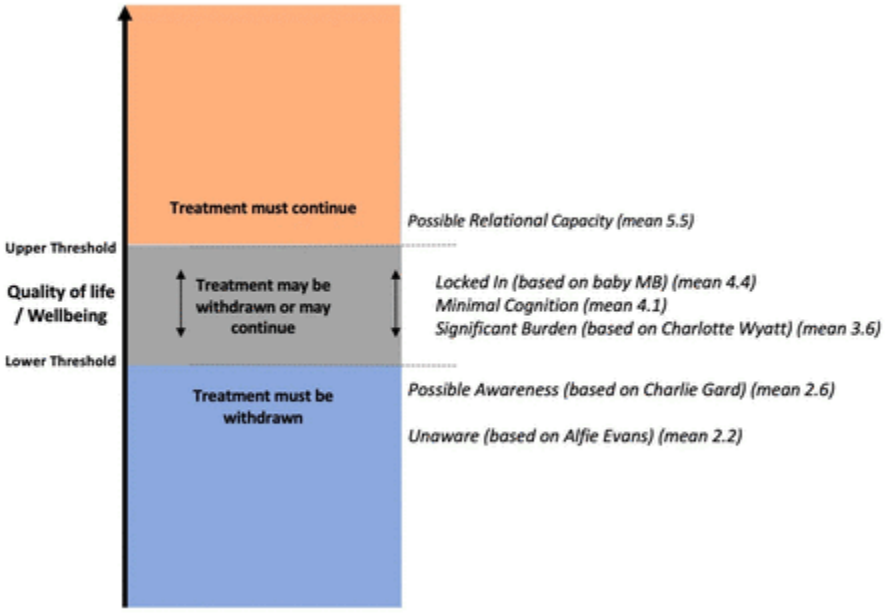
an absolute tragedy. The goal is not to reduce the amount of prenatal genetic testing, but the objective is to recognize and prevent ableist tendencies within the process in order to better care for patients and future children with positive prenatal genetic testing results. Informing patients of positive prenatal genetic testing results should not consist of phrasing like "unfortunately your test results are not normal". Clearly parents want a child who does not have to undergo pain or hardship, however the presence of a positive genetic test that can be indicative of disability should not immediately be seen as undesirable and unlucky. In these cases the medical professional is signifying that the disability is directly correlated with suffering, but this also creates nervousness for the patient and the anticipation that a disabled fetus is unsuitable to be of the same standard as a "normal" fetus. Many ableist perceptions reiterated by society contribute to the tragedy trope of disability. As explained by Saxton (2006), the belief that prenatal genetic testing is driven by reassurance can shield an alternative motive that screening out disabled fetuses is the proper thing to do. This can evolve into individuals with disabilities being given disproportionate opportunities to thrive.

A Disabled Life is not Worth Living

Society continuously reinforces the suggestion that having a disability is a tragic, forlorn aspect of an individual's life. This can be manifested in ways such as people saying that they "would rather be dead" than to live with a certain disability, or that the death of someone with a disability would finally allow them to be "free of their misery". Statements like these represent the ableist justification that a disabled life is not worth living. A study done by Brick et al. (2020) explored attitudes upon deciding when disabled children should no longer live, and the

study found that 94% of participants supported the idea that significantly disabled infant life is not valuable enough to be continued.

Figure 2



This figure taken from Birk et al. displays the Threshold Framework that represents quality of life versus morally acceptable time to withdrawal treatment based upon the study results. The figure shows how when an individual is perceived to have an adequate quality of life, most people support continuation of treatment. As quality of life declines and enters the lower threshold, support to withdraw treatment presents itself. Quality of life is complex and not easily defined, however this study values quality of life as based upon the ability to obtain relationships and have future abilities. This figure was retrieved from Brick C, Kahane G, Wilkinson D, et al. Worth living or worth dying? The views of the general public about allowing disabled children to die Journal of Medical Ethics 2020;46:7-15. http://dx.doi.org/10.1136/medethics-2019-105639; released under a CC BY 4.0 license. No changes were made.

Public opinion about the worthiness of life within disabled children is relevant when considering public opinions on prenatal genetic testing. People believe that continuation of life for individuals with severe disabilities that are dependent on complex treatment is not desirable. Beliefs like this reflect the decisions of many during the prenatal genetic testing process, as parents who receive diagnoses of a significantly disabled fetus may opt for abortion secondary to the diagnosis. They conclude that bringing a child who is expected to have many serious disabilities into life would yield little to no quality of life, therefore prevention of birth opts the fetus out of possible suffering and distress. As the medical field advances, treatment will become more effective for more serious health complications. This makes deciding when to reach a stopping point of treatment a difficult decision, hence why many choose to evaluate quality of life.

Even though the quality of life argument is frequently used, the quality of life argument is not dependable. Peter Singer, an ethicist and utilitarian who remains a prominent figure in bioethics, has a history of publically making harsh comments against the disability community. As described by McPherson and Sobsery (2003), Singer believes that infants with various genetic disabilities should be candidates for extermination secondary to the fact that their happiness can be limited due to their disability, as well as that individuals with severe disabilities are not of equal moral status and experience a very lower quality of life. This is only one example of an educated, influential, and nondisabled individual presenting the idea that a disabled life is not worth living. McPherson and Sobsery (2003) dispute Singer's argument stating that individuals with disabilities themselves rate their quality of life to the same extent as do nondisabled individuals, and nondisabled individuals misjudge the quality of life for disabled

individuals. Historically, disability is deemed as an insignificant form when compared to the typical individual, and these intentions have carried into the present to manifest themselves as arguments that recognize disabled infants as being incapable of full humanity, consequently not entitled to the right to exist (Lewiecki-Wilson, 2011). Socially ingrained ableism leads to misconstructed societal beliefs about the disability experience, leading to doubtful assumptions when evaluating the value of the disabled person's life.

Another harmful example of how society presents the belief that a disabled life is not worth living is physician assisted suicide. Physician assisted suicide may be advantageous on a case by case basis, but physician assisted suicide of disabled individuals will be concentrated upon. An arguement for physician assisted suicide used within the healthcare system is the idea of "death with dignity". This illustrates that individuals with significant disabilities are suffering to such an extent that they should be able to choose when they will die in order to prevent experiencing an unpleasant quality of life. Defining dignity is a frequently debated concept. Utilization of the word dignity can lead to the assumption that living with the disability is an indignity associated with shame and loss of respect and that obtaining dignity is based upon the quality of the physical health and able-bodiedness, both of which contribute to devaluing disability (Behuniak, 2011). The phenomenon of death with dignity has the ability to be misconstrued by ableist values of society, as a satisfactory state of life is associated with the nondisabled body and deviation from this is assumed to be dissatisfactory. A national disability rights group called Not Dead Yet (2022) strongly opposes physician assisted suicide and euthanasia and suggests that it is discriminative by targeting lives of disabled, old, and ill people for "mercy killings". Not Dead Yet provides explantions for their opposition including that disability is the issue, physicians misjudge the quality of life, physician assisted suicide will be

favored due to massive health care budget cuts, life sustaining treatment will be denied by healthcare professionals, and that loss of a disabled life is acceptable since disability is often seen as worse than death (2022).

The same concerns can also be applied to prenatal genetic testing. Medical professionals fail to recognize possible enrichment of life with a disability, the extent to which an identified fetal disability diagnosis impacts quality of life is inaccurate, abortion of disabled fetuses ultimately saves money within the health care, abortion is seen as the only option of pregnancy continuation rather than opting for complex treatment of genetic disease, and choosing to terminate the disabled fetus is interpreted as the merciful and sensible option. Prenatal genetic testing can lead to diagnosis of genetic diseases. Eckberg (2007) explains the most beneficial aspects of prenatal genetic testing as being "the prevention of the birth of a child with chronic genetic disease and offering parents a degree of liberation from reproductive risk". This statement directly shows how society could weaponize the prenatal genetic testing process against the disability community through beliefs that terminating a pregnancy solely due to the presence of a genetic disease will allow the expecting parents to be free from the imprisonment and oppression associated with disability. Hurtful beliefs similar to this may be held not only by patients but also by medical professionals. Based on the diagnosis of genetic diseases in utero, medical professionals will interpret the results and inform their patients. Utilization of the medical model of disability can contribute to misjudgement of possible quality of life, as the assumption that an incurable disease equates to a tragic, unproductive quality of life is implied. Medical professionals may pressure patient's into having an abortion because death seems as a more acceptable option rather than living with a disability. Healthcare professionals may assume that caring for the baby that is positive for genetic diseases may be unproductive, as life

sustaining treatment can be extremely expensive and demanding. Ableist perceptions in society transfer the idea that disability is the problem instead of recognizing the lack of disability resources and exploring methods to better manage a disability. Society does not consider the abortion of a disabled fetus to the same extent as the abortion of a typical fetus deemed as healthy. As explained by Manninen (2015), the blatant expectation for a disabled fetus is abortion since they can be replaced with a typical fetus. Society does not take a disabled life seriously and views disabled lives as expendable. Abortion of a disabled fetus is assumed just because of the negative connotation associated with disability instead of abortion being an autonomous choice based on a multiplicity of factors within the pregnant person's life. Dehumanization of the disabled fetus allows for easier acceptance that a disabled life is not worth living. Manninen (2015) references a personal experience with a mother whose pregnancy was at high risk for genetic disease where her peers and medical professionals began to refer to the fetus as "it" rather than "her" or "baby" like they were prior to testing, thus creating a disconnect and depreciation of the disabled fetus. Patients should be adequately educated on the prenatal genetic testing results in a way that they feel comfortable with making their own personal decisions in how to proceed rather than feeling pressured to have an abortion or feeling doomed that the life of them and their baby will be devastating secondary to the possible consequences of a disability. It is important to recognize how prenatal genetic testing does not specifically prevent genetic disease, but instead prevents births of individuals affected by genetic disease (Andrews et al., 1994).

Disability Makes People Expect Less

Fused with the idea that a disabled life is not worth living is the belief that the presence of a disability warrants lower expectations for the individual in terms of capabilities and quality of

life. Fundamentally, individuals with disabilities are instantly held to a lower expectation secondary to ableist beliefs that disabled people are not capable of being functional members in society. Historically, the ableist attitudes of society instigate actions of isolating the disability community from the rest of society due to inaccurate associations of disability with uselessness. This can be labeled as one of the attitudinal barriers disabled people face, where the person is ignored and only the impairment is concentrated upon (EPIC Employment Inc, 2021). In terms of prenatal genetic testing, it is possible for expecting parents and associated medical professionals to only focus attention on a positive prenatal genetic testing result and interpret it as unpromising, leading to little optimism regarding the progression of the pregnancy. The phenomenon of disability spread contributes to society's lowered expectations for disabled people. Disability spread is the fallacy that one impairment limits other aspects in life although they are realistically unassociated. This leads to the belief that the presence of the particular impairment the fetus tested positive for will impact all of their life abilities in a negative way. Focusing only upon the detrimental effects that the fetus may endure rather than accurately educating expecting parents how they could manage possible consequences with the current resources available influences people to have little hope and confidence in the continuation of the pregnancy. Instead of the pregnancy being an exciting journey for expecting parents, it becomes an unfortunate and distressing process. Reduced expectations due to disability lead to "a wanted baby turning into an unwanted fetus" (Saxton, 2006). A planned pregnancy that was seen as a blessing quickly morphs into an encumbrance. Furthermore, the idea that disability is associated with lowered expectations can be seen with how society responds to a pregnancy with a known disabled fetus. Mothers with known healthy fetuses will be surrounded with excitement and anticipation, while mothers carrying disabled fetuses may be called "strong", "brave", or

"fearless". Women carrying disabled fetuses are treated differently since society is not only shocked that the woman chose to continue the pregnancy, but also due to the belief that the fetus will cause suffering to the mother due to the inadequacy of the fetus. Medical professions may transfer this bias into the care of patients undergoing prenatal genetic testing. This may be in the form of assuming the mother will opt for abortion, persuading the mother to end the pregnancy, or insufficiently providing resources needed to interpret positive prenatal genetic testing results,

Outcomes of the Wrongful Birth Argument

Individuals of society have explored the option of taking legal action against medical professionals when their child is born with a birth defect, which has been coined as wrongful birth lawsuits. With the available technology of prenatal genetic testing, patients may be convinced that prenatal genetic testing would have identified the birth defect and offered them the choice of abortion if the medical professional would have advocated for it. This phenomenon has offered the opportunity for patients to sue doctors responsible for wrongful birth in an attempt to compensate for the "suffering" the child endured upon birth and in life. Weil (2006) explores the argument of how wrongful birth can be determined as a type of medical negligence if parents were not given the opportunity to identify the impairment and ultimately terminate the pregnancy after this, and Weil mentions how Bioethicist Leon Kass further elaborates saying "the only way to cure the illness is to prevent the patient". Ultimately the agenda of such lawsuits against medical professionals communicates that the birth of disabled children should be prevented. This argument holds for many even when considering nonterminal disabilities, such as Down Syndrome, which unmistakingly shows disability discrimination within our society. Patients who birth disabled children are convinced that taking legal action against medical

professionals that did not prematurely inform them of the fetus's impairment will be effective in compensating for the disabled child they wish they had terminated. While it is clear that the healthcare system often fails to provide adequate resources for some aspects of disability or that treatment may fail for multiple chronic conditions associated with genetic disease, this statement essentially passes on the message that medical professionals need to recognize disability of the fetus to allow for termination of the pregnancy. This not only contributes to the ableist idea that a disabled life is not worth living, but it is also serving as an incentive for medical professionals to persuade patients into completing prenatal genetic testing, even if that was not part of their original plan. This can also lead to encouraging abortion, where legalized, when prenatal genetic testing is positive. Medical professionals including physicians, genetic testing laboratories, and genetic counselors can face lawsuits if parents declare that they were not informed of prenatal genetic testing availability or if the testing was performed or interpreted incorrectly when their child is born with a birth defect, even when the interpretation of defect expands as the prenatal genetic testing field advances (Sullivan, 2000). Lawsuits based on the circumstances of birth defects offer an entirely new area of concern. Due to so many healthcare providers being liable, this may influence health care providers to pressurize or coerce patients into completing the prenatal genetic testing process. Extending beyond this, parents who deem the life of their possibly disabled child as improper and unlawful also reinforce ableist conceptions that disability is unsuitable for life. The term "wrongful birth" in itself exhibits ableism and is suggestive to the eugenics past of disability.

Possibility of Eugenics and Sterilization Perpetuation

As described by Liscum and Garcia (2022), the ultimate goal of modern genetics correlates with the goal of the eugenics movement, to eliminate disease. The disability community has been historically treated as inferior and this can be exhibited with investigation of eugenics and sterilization. Society has continuously made efforts to minimize disability for many years, whether through preventing the birth of disabled people or preventing the ability of a disabled person to pass on heritable aspects of disability. Sterilization was legally established seen in the Buck v Bell supreme court case stating that individuals in state institutions, often individuals who had been diagnosed with mental illness among other disabilities, could be involuntarily sterilized justified by the statement that "three generations of imbeciles are enough" (Powell, 2020). This law has yet to be officially and legally overturned. This demonstrates how both society and healthcare aimed to limit disabled individuals, and ableism remains so influential today that no attention has been brought to these discriminatory laws.

Eugenics concentrated on the use of selective procreation in efforts to eliminate social ills, with physicians having been the most substantial advocators (Lombardo, 1996). Physicians encouraged the eugenics movement based on the belief of its ability to enhance the human race based upon prevention of births seen as reprehensible. In the present prenatal genetic testing is used to prematurely identify genetic diseases prior to the birth of a fetus, with physicians and other medical professionals being the most influential people involved. As a result it is rational to consider if goals of bettering the human race by minimizing birth of the "undesirable" could be implemented in the prenatal genetic testing process by medical professionals today. United Nations' disability expert expressed her concern by explaining how advancement of prenatal genetic testing and other achievements in genetics offer methods of human improvement capable of reintroducing eugenics fueled by ableism ("New eugenics: UN disability expert warns against

'ableism' in medical practice", 2020). Prenatal genetic testing is also ethically challenging due to the negative judgment of individuals that tested positive for conditions that can insinuate adversary consequences (Allyse & Michie, 2022). Expecting parents aspire to have children in good condition with satisfactory well being. Prenatal genetic testing may be presented to them by medical professionals as an opportunity to sift out any chances of children that have genetically identifiable traits associated with an altered state of health. This can instill fear in expecting parents, making them opt for the selection of "desirable" fetuses in an attempt to protect themselves and their future child. Eugenic abortions instigate concern as they can "reinforce discriminatory attitudes towards those selected against" (Allyse and Michie, 2022).

The trend of "designer babies" encapsulates the continuous eugenic inclination present in today's society. The main goal of creating designer babies is to limit heritable genetic diseases by using preimplantation genetic diagnosis or genetic modification in the IVF process to select "disease free" embryos (Pang & Ho, 2016). This process differs from prenatal genetic testing as there is testing and modification of the embryo prior to implantation. Many ethical concerns have been raised when investigating designer babies. Researchers Pang and Ho (2016) deemed techniques for designer babies as not ready for clinical application and warranting further long term investigation of their safety. Prenatal genetic testing evaluates an actual fetus, much past the preimplantation stage utilized within the production of designer babies. If the "designer baby" process with goals of preventing diseased embryos was found to warrant further investigation, then it is likely that the process of testing for and managing "diseased" fetuses also warrants investigation.

Unjustified discrimination against Down syndrome as a precedent for other genetic diseases

Trisomy 21, most predominantly known as Down syndrome (DS), is an easily identifiable genetic disease found in prenatal genetic testing. Down syndrome withholds significant stigma within society and the healthcare system. It is important to first acknowledge the significant health complications associated with Down Syndrome. Down Syndrome involves various manifestations including:

> "muscle hypotonia, atlantoaxial instability, reduced neuronal density, cerebellar hypoplasia, intellectual disability and congenital heart defects (CHDs; particularly atrioventricular septal defects (AVSDs)). Individuals with DS are also more likely to develop certain health conditions, including hypothyroidism, autoimmune diseases, obstructive sleep apnoea, epilepsy, hearing and vision problems, haematological disorders (including leukaemia), recurrent infections, anxiety disorders and early-onset Alzheimer disease (AD)" (Antonarakis et al., 2020).

While it is certain that there will be health complications due to Down Syndrome, the disease now has a live expectancy of 53 to 58 as of 2010 (Antonarakis et al., 2020).

There are obvious discriminative beliefs towards Down syndrome in the prenatal genetic testing process. Failing to recognize this massive discrimination not only allows for the fallacies regarding Down syndrome that are fueled by ableism to continue, but it also creates a framework for how other detected genetic diseases should be treated. Kellog et al. (2014) investigated the attitudes of mothers who have children with Down syndrome regarding noninvasive prenatal testing (NIPT) and found that the participants believed that NIPT could lead to "increased terminations (88%), increased social stigma (57%), and decreased availability of services for

individuals with Down syndrome", additionally 48% believed that healthcare professionals exhibited inaccurate and biased information during the diagnosis, leading to 24% believing that the unreliable information may have contributed to termination of pregnancies with Down syndrome diagnoses. The significant response about healthcare professionals being biased, inaccurate, and unreliable should raise great concern. Patients count on healthcare professionals to adequately and correctly inform them of the expectations of a disease, such as Down Syndrome, in the prenatal genetic testing process. The failure to do so shows the lack of patient advocacy that can massively influence decision making of many pregnant patients. In 2012, 67% of patients in the United States opted for pregnancy termination post trisomy 21 diagnosis (Raymond et al., 2022). Other countries obtain even higher rates of abortion due to trisomy 21 diagnosis. A CBS news story found that nearly 100% of trisomy 21 diagnoses from prenatal screening led to pregnancy termination in Iceland, with a geneticist mentioning the country has nearly "eradicated" Down Syndrome ("What kind of society do you want to live in?", 2017). The goal of eliminating an entire group, such as the Down Syndrome, can be eerily similar as to what was seen in the past with eugenics. Mandated genetic testing for genetic risk or disability can be perceived as an attempt of eradication and as a disavowal of worth for those with the disability or genetic risk (Andrews et al., 1994). Prenatal genetic testing identifies fetal abnormalities consistent with Down Syndrome, allowing people to have an outlet for the eradication of the Down syndrome community often validated by discriminatory preconceptions rather than scientific facts. Manninen (2015) explains that 23% of primary care providers highlighted negative aspects of Down Syndrome in an attempt to urge to pregnancy termination, furthermore that obstetricians often express that termination of pregnancy with a fetus diagnosed with the Down Syndrome as the obvious and sensible choice and would go great lengths to aid the patient

is receiving abortion care despite the lack of the patient showing interest in abortion. Instead of exploring options with the patient and thoroughly informing expecting parents of what may come in the future, the diagnosis is immediately seen as undesirable and warranting abortion without further exploration. Medical professionals should be focused upon patient care and the wishes of patients. The medical professionals should not be attempting to frighten patients into pregnancy termination in an attempt to prevent future "suffering" based upon a positive prenatal genetic test. The ability for an individual with Down Syndrome to live a fulfilling, high quality life is possible when given the right resources and access, but ableist perceptions convince society that this is not feasible. Physicians are unwilling to respect continuation of pregnancy with a disabling trait, as the ability for nourishment of a disabled child within a family is considered infeasible (Asch & Parens, 2000).

The disability community recognizes this discrimination, yet there has been minimal advocacy for change within the healthcare system. Disability based organizations such as Don't Screen us Out and Save Down Syndrome aim to spread awareness toward the unequal treatment towards the Down Syndrome Community. Don't Screen Us Out strives toward the goal of babies with Down syndrome being given equal opportunities to be born, and efforts to reach this goal are based in modifying the problematic attitudes of society (Don't Screen Us Out, n.d.). Save Down Syndrome explains how people with Down Syndrome can reach the same accomplishments as those without Down Syndrome when they are not treated differently secondary to their disability. The possible eradication of the Down Syndrome community is a real concern in relation to the expansion of prenatal genetic testing. According to Mayor (2007), after the availability of non-invasive prenatal screening was extended to more women in Denmark, the number of births with Down syndrome was cut in half in a matter of three years.

Trends like this may apply to communities of other diseases, as the discriminatory behavior currently exhibited toward Down Syndrome can set a precedent for other genetic diseases that can be identified through prenatal genetic testing. Companies in prenatal genetic testing are expanding their range for identifiable genetic diseases, including sex chromosome aneuploidies. Sex chromosome aneuploidies are fairly common (1 in 400 births), but are very irregular and often have unpredictable presentations (Riggan et al., 2021). Many sex chromosome aneuploidies have a more mild prognosis, however the ability to detect the aneuploidies via prenatal genetic testing may warrant people to select for pregnancy termination despite this. Similar to Down Syndrome, other aneuploidies that have less severe courses of disease may be urged towards elimination. As the field of genetic testing advances, it is crucial to be conscious of expanded ability to detect genetic diseases, as this puts more genetic diseases and disabilities at risk for eradication attempts in the future.

Disabled people are part of an unrecognized health disparity

The health disparities based upon race, gender, sexual orientation, or ethnicity are much more well documented when compared to health disparities based upon disability status. This directly reflects how public health often treats the disability community disproportionately. The World Health Organization established that the Internal Classification of Functioning Disability and Health serves as the most suitable framework of disability that should be applied in public health, however application of this framework within America is delayed due to the traditional predominant use of the medical model that rejects the integration of environmental factors into the management of disability and due to the modifications of the billings systems that would be required (Krahn et al., 2015). The healthcare system continuously rejects the proposal to explore

disability as an integrative medical, environmental, and social experience, and instead treats disability as an inferior, disruptive quality of an individual. Not only does the healthcare system fail to implement proper comprehensive framework when managing disability, it fails to treat nondisabled and disabled individuals to the same degree. Patients with disabilities have been shown to be at higher risk for premature death, for developing severe medical complications and for preventable chronic conditions, as well as experiencing other unmet healthcare needs (Meade et al., 2015). Ladu et al. (2022) created 3 focus groups of US physicians for qualitative analysis and found obvious disability discrimination including purposefully denying and discharged patients based upon them having a disability and expression of ableist attitudes, ultimately displaying how both physician bias and hesitancy to treated people with disabilities exacerbates disability health disparities. Disability health disparities are carried over into the prenatal genetic testing process. Throughout the process, medical providers may continuously practice the medical model, reinforcing harmful stereotypes that lead to misinformation about disability. Correspondingly, if the fetus is diagnosed with a disability via prenatal genetic testing, the healthcare system may fail to provide sufficient medical management of the possibly disabled fetus. Alternatively, parents expecting a child with nontypical prenatal genetic testing results may obtain fear of feasible health disparities and unmet healthcare needs their child may face in the future secondary to their disability. The fear about the possible consequences may influence expecting parents to terminate the pregnancy in an attempt to prevent the possibility of unfortunate circumstances faced by their child in the future due to disability health disparities. If patients with disabilities did not face such vast inequality within public health, many expecting parents may have been prompted to continue with the pregnancy. The disrespect towards the disability community and the lack of acknowledging ableism is seen within the values of health

organizations including the CDC, NIH, American Genetic Association, and Planned Parenthood. The unfair health disparities tolerated by the disability community will continue if influential health organizations pay no attention to the notable influences of ableism within the healthcare system.

4. PROCEEDING WITH PRENATAL GENETIC TESTING APPROPRIATELY

Prenatal genetic testing will only continue to increase in prevalence. Despite its present popularity, first hand experiences of the patients that undergo the testing is largely unobserved. A study exploring the experiences of women undergoing prenatal genetic testing revealed themes of "an offer too good to pass up, blindsighted by the results, uncertainty and unidentifiable risks, need for support, and toxic knowledge" in turn warranting the need for better counseling, education, and resources for providers (Bernhardt et al., 2013). Prenatal genetic testing obtains many beneficial qualities, and ethical interpretation of the process does not intend to advocate for reduction of prenatal genetic testing. Instead it is crucial that medical professionals involved in the process properly educate themselves in order to provide patients with informed decision making and satisfactory patient advocacy. In order to do this, the ableist approach to prenatal genetic testing must be eliminated.

Implementing Changes to Reduce Ableism

The lack of acknowledgement to how the medical field often exhibits ableism is a major issue, despite the possible methods of ableism reduction. Reduction of ableism can be completed by transitioning from the medical model of disability to the social model of disability. The medical model is centralized on how the disability will limit the individual, and these limitations

will only be solved if the disabilities are prevented or cured. Through the perception of the medical model a person will only be seen as equal to nondisabled members of society if their disabilities are cured. Contrastingly, the social model defines disability as “the loss or limitation of opportunities to take part in the life of a community on an equal level with others" (Burchardt, 2004). Through the social model, lost or limited opportunities associated with disability are actually due to societal factors such as limited access and disability based discrimination rather than the actual impairments of the individual. The medical model can manifest itself within the PGT process through equating disabled fetuses as tragic, wasted labor, impractical, and obligated to be aborted. Utilization of the social model can portray a disabled fetus as obtaining impairments that have the potential to be non disabling through adequate integration within society by means of proper resources and accommodations. The social model can be exhibited by medical professionals through accurately communicating health complications associated with identifiable genetic diseases, discussing how to achieve access to proper resources, incorporating viewpoints of the disability experience, and thoughtfully considering how a pregnancy with a disabled fetus can continue. This can be seen through minimizing persuasion towards completion of prenatal genetic testing, adequately explaining the advantages and possible consequences of prenatal genetic testing, and ensuring that the prenatal genetic testing is being done for the sake of voluntary knowledge of fetal condition rather than for prevention of disabilities. Prenatal genetic testing can be advocated for while simultaneously affirming the value of life for people with disabilities. Altogether, recognizing how the interpretation of disability by the medical field within the prenatal genetic testing process contributes to ableism and implementing accurate approaches of disability can decrease healthcare disparities faced by patients and increase patient satisfaction. Disability should not be solely framed as a medical

condition that is devastating if there is no cure available, and the obvious discriminatory attitudes towards disability must be disposed of. Medical professionals involved within the prenatal genetic testing process should have expectations of being unbiased and educated about disability ethics at the minimum. Having said that, some medical professionals involved in the prenatal genetic testing process may not feel qualified to an extent that allows them to explain accurate portrayals of disability based on genetic testing results to their patients.

Prioritize Precaution rather than Delayed Management

Another method of reducing ableist perceptions in the PGT process that negatively impacts decision making would be to focus on prevention rather than removal. Prenatal genetic testing is only one of the many processes within the American healthcare system that could be improved through better precautionary efforts. Transitioning from sick care to the prevention model through acting in advance to prevent manifestation of a disease can help solve the current crisis of the US healthcare system (Marvasti and Stafford, 2012). Although the prevention model is focused on applications to chronic diseases, it may also be applied with genetic diseases. Prenatal genetic testing does not stop genetic diseases from happening. PGT is able to reduce the amount of children born with genetic diseases by recognizing the genetic disease in utero and prompting the pregnant patient to pursue an abortion. PGT does not decrease incidences of genetic diseases, but instead decreases births of children with identifiable genetic diseases. Genetic diseases that are often found with PGT can be minimized through carrier screening. Since prenatal genetic testing is voluntary and aims to act as knowledge related to fetal condition, prospective parents with extensive concern for the genetic condition of anticipated children have the option to complete carrier screening. Carrier screening of both the egg and

sperm contributors can provide information regarding risk for heritable genetic diseases, which are often rare genetic disorders associated with significant health complications. Azimi et al. (2016) concluded that carrier screening in collaboration with genetic counseling was able to significantly reduce occurrences of recessive genetic disorders, and it allowed for thorough information about reproductive risk for prospective parents. With carrier screening genetic risk can be prematurely identified, so individuals can proceed with pregnancy plans with precaution. If individuals believe the risk is too great for them, they can opt for other methods of attaining a child. This allows for thorough education regarding genetic disease prior to pregnancy, which can lead to more informed decision making when following through with pregnancy and prenatal genetic testing. According to Azimi et al. (2016) next-generation carrier screening reduced incidences of births affected by detectable recessive genetic diseases by 61%, which reduced cost by 66%, which translates into millions of dollars in saved lifetime costs. This offers prospective parents who have concern for genetic disorders in their children the opportunity to assess their risk prior to getting pregnant and allows for in depth assessment of their financial risk if they chose to get pregnant. The pregnancy of a possibly affected child can be diverted preconception rather than genetic disease being assessed and managed for postconception. Although carrier screening is a great available option, there are limitations as not all pregnancies are planned, there are accessibility complications to carrier screening (such as health insurance or financial barriers), and not all genetic diseases detected by PGT, such as chromosomal aneuploidies, are able to be predicted by carrier testing.

Evaluating Scope of Practice and Recognizing Lack of Resources

It is crucial that medical professionals, like OB/GYNs, exhibit proper disability related ethics within their patient care. With this in mind it is also important to consider their scope of practice, which may have consisted of minimal disability related education, especially related to social factors and genetic testing. The intention of OB/GYN medical professionals is to treat pregnant patients and inform expecting parents of the fetal condition. Instructing patients on complex genetic testing findings and conversing about welfare of those disabilities may be outside of their field of reference. This role is typically filled by genetic counselors, however as the frequency of prenatal genetic testing increases, there is a shortage of genetic services. This may yield OB/GYNs expanding their role of genetic counseling to outside their comfortability (Bayefsky et al., 2016). The role of the OB/GYN within this process will need to be reevaluated to better manage limitations of their role and to reduce increased burden on their workload. Iezzoni et al. (2021) surveyed 714 practicing US physicians and discovered that only 40.7% of exhibited high confidence in their potential to treat disabled individuals to the same extent as non-disabled individuals, 56.5% strongly agreed that people with disabilities were welcomed to be under their care, and 18.7% of participants strongly agreed that people with disabilities often are treated unfairly in the healthcare system. These statistics are staggering, as the majority of the physicians are not able to confidently say that they can treat disabled patients equitably, are not able to confidently accept people with disabilities under their care, and are not able to recognize the discrimination the healthcare system exhibits toward the disability community. A similar level of discomfort applies to the prenatal genetic testing process. Benn et al. (2013) surveyed Fellows of the American College of Obstetricians and Gynecologists and discovered that 33% were comfortable with counseling patients about carrier screening, and 24.9% were comfortable with explaining the results of the testing, furthermore while 49% of respondents reported having

had a genetic counselor available. Studies similar to this show how OB/GYNs are not comfortable with nor are they proficient with explaining methods and results of prenatal genetic testing to their patients who depend on them for accuracy and thorough knowledge. This flawed provider to patient communication harms the patients who typically do not have access to tools that explain the PGT process. Colicchia et al. (2016) found only 1.1% of genetic counseling provided by healthcare providers met all College-recommended topics. This represents the dire need for better preparation of OB/GYNs to explain PGT and the increased demand for genetic services. Genetic services are currently limited due to increased demand, however strategies like Telehealth, incorporation of genetic counselors into clinics, group genetic counseling, and provider to provider training could help alleviate the shortage and improve outcomes for patients (Raspa et al., 2021).

Outlets for patient education on prenatal genetic testing could also alleviate the strain on both OB/GYNs and genetic services. The entirety of the healthcare system involved in fetal care needs to better accommodate for the increased levels of prenatal genetic testing through providing more available resources including but not limited to support groups, genetic counseling, and public informative resources. In order to compensate for the lack of education on prenatal genetic testing, standard resources such as videos, websites, and pamphlets may be beneficial. There is currently a lack of resources defining what prenatal genetic testing is, how it is applied, and who is responsible for choosing to do it at a civilian level of comprehensiveness. The American College of Obstetrics and Gynecology has guidelines for pregnant women about PGT, however these recommendations are not readily accessible for many expectant parents (Mills, 2022). Availability of comprehensible material that can lead to more informed consent will be helpful for patients. Stortz et al. (2023) found that when showing an educational video on

prenatal genetic testing, there was improval of knowledge and a decrease of decisional conflict and regret. Educational and accessible resources are likely efficient in providing accurate information about PGT and informed decision making, ultimately buffering the consequences of limited genetic services and unclear scope of practice of OB/GYNs.

Avoid the Dangers of For-profit Incentives

Although PGT is marketed as a cost-effective resource, it is important to avoid a for-profit mentality within the prenatal genetic testing process. There are several for-profit concerns within the PGT process. The decision of having a child should not be massively affected by the "cost-effectiveness" of bringing the child to life. While it is important to be financially secure when deciding to have a child, the decision to have a child should not only be influenced by the possible financial consequences based on a medical condition. A disabled life should be labeled with an expensive price tag and warranted as unworthy because of it. Evaluation of how society and the healthcare system contribute to high-priced care of those with disabilities using the social model could provide more logical explanations and management. It is also important to consider that as the field of genetic testing gets more competitive, companies involved in the process will evolve to gain profit, potentially adversely affecting patients and medical providers along the way. According to Allyse & Chandrasekharan (2015), noninvasive prenatal screening (NIPS) is rapidly expanding to include information of arguable clinical utility, including by not limited to identification of biological sex, microdeletions, and sex chromosome aneuploidies, and the motives behind rapid expansion of NIPS is driven by profit in some measure. The clinical intent of prenatal genetic testing is to prematurely identify possible health complications in order to better protect and care for both the pregnant patient, or

prospective parents, and the unborn child. The process should not be urged to expand as a result of capitalist motives from the companies that create the genetic tests. Additionally, medical professionals involved may opt to advocate for testing to avoid possible expenses of potential legal actions by patients. Legal actions could include the Wrongful Birth lawsuit. Inappropriate financial motives involved in the process must be considered and re-evaluated by both medical professionals and patients.

5. CONCLUSION

Prenatal genetic testing has an abundance of ethical concerns. The impact of ableism on decision making in the PGT process is a substantial ethical concern that is not acknowledged both by society and the medical field. Ethical evaluation of the relationship between disability discrimination and prenatal genetic testing is needed secondary to the rapid expansion of PGT. As the range of identifiable genetic diseases or abnormalities detectable in utero expands, the disability community is further put at risk for inequity. Ableist preconceptions depreciate the worthiness of a disabled life, miscalculate a person with a disability's quality of life, and ignore the pronounced health disparities faced by the disability community. Fixed ableism within society is exacerbated by the strict medical model of disability reiterated by medical professionals. The impact of ableism within PGT is further worsened by the lack of genetic services available, unclear communication between pregnant patients and their OB/GYN providers, and the scarcity of self-informing resources available to patients seeking PGT. As the field of prenatal genetic testing expands and claims that PGT "reduces" disability, ultimately leading to better health of fetuses, it is reasonable to consider that PGT may become a required aspect of prenatal care. The possibility of prenatal genetic testing standardization should be

evaluated and questioned. Mandating PGT for all pregnant patients could lead to harmful consequences. The main objective of prenatal genetic testing is to offer expectant parents reproductive choices and independent decision making. Government intervention making prenatal genetic testing a prenatal care requirement leads to eugenics and autonomy concerns. Given all the current flaws within the PGT process, necessitating all pregnant patients to undergo prenatal genetic testing would only exacerbate problems including but not limited to lack of genetic services resources, ableism, unsettled scope of practice for medical professionals, and eugenics reiteration through abolishment of some identifiable genetic diseases.

7. RECOMMENDATIONS

The interaction between patients and healthcare professionals related to PGT must be improved through cohesive communication. This communication should convey accurate portrayals of disability ingrained with both the social and medical models of disability. Prior to completion of PGT, pregnant patients should be thoroughly informed of the possibilities of false positives and false negatives, and they should be knowledgeable regarding the implications and consequences of prenatal genetic testing. Medical professionals should comprehensively discuss how PGT is completely voluntary and what options are available depending on the test results. Patients seeking PGT must be their own advocates rather than falling under pressure from their medical professionals to take part in PGT in an attempt to affirm to them that their baby is “normal”. Improval of these aspects can strengthen the informative, uncoerced decision making of patients, and the overall patient experience. Prenatal genetic testing is only one of the many phenomenons where disabled people are treated as inferior. Moving forward medical professionals should be taught ableism just as they are taught about other forms of

discrimination, and society must stop undervaluing the disability community through ableist perceptions. Research regarding the impacts of ableism within the prenatal genetic testing process is scarce. Examination of experiences of people involved with the prenatal genetic testing process would generate better assessment of how to manage and prevent further impacts of ableism in the PGT process.

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