

Heading *Down* the Right Path: The Future of Prenatal Testing for Trisomy 21

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Until recently, the two primary methods by which fetuses were tested for Down Syndrome were amniocentesis and chorionic villus sampling, both of which are invasive and pose a risk of miscarriage. Thanks to a novel non-invasive prenatal test (NIPT), women can discover with near certainty whether their fetus will be born with Down Syndrome easily, early on in the pregnancy, and entirely safely. This has sparked a tremendous debate regarding the moral permissibility of the test – we are trapped between a desire to provide women with the most information possible regarding their pregnancies and concerns regarding the rights of the fetus, as the only solution that eliminates the diagnosis in the case of a positive test is the termination of the pregnancy. There are two main arguments in the literature positioned against prenatal testing for Down Syndrome, one of which is deontological and the other teleological, neither of which is morally persuasive. After examining both of these arguments and the responses to them, I will demonstrate that we are morally obligated to present this test to all pregnant women in the early stages of their pregnancies and encourage them to take it. For this process to be ethical, however, true autonomy must be maintained through complete freedom of information in the form of nondirective counseling. This is conducive to the mental, physical, and emotional well-being of all children, and will ensure their best lives and proper care above all else.

Introduction

“I am a man with Down Syndrome and my life is worth living!” (Friedersdorf). In October of 2017, Special Olympian and disability rights advocate Frank Stephens testified before Congress with this statement, imploring for the National Institutes of Health to devote more of its budget to Down Syndrome research. In addition to Stephens, children and adults with Down Syndrome have been strongly asserting as of late that they have satisfying lives filled with love, joy, and achievement. Take, for example, one-year-old Lucas Warren, the Gerber spokesbaby selected in 2018. For the first time since the advent of the annual contest in the 1920s, the corporation selected a child with Down Syndrome as the face of the company, allowing Lucas’ parents to speak out about the importance of representing Down Syndrome in the media. His mother proudly spoke about the company’s inclusive decision, proclaiming, “We believe that if brands represent children with a disability, they are communicating their value to society” (Today). This new push to portray happy children and adults with Down Syndrome has come about as a result of the novel prenatal genetic test that can indicate to mothers with near certainty whether or not their child will have Down Syndrome.

Testing for Down Syndrome has been available for decades, but until recently, it has carried with it

an associated risk of miscarriage. With the advent of noninvasive prenatal testing (NIPT) in 1997 and its introduction into clinical practice in 2011, there is no longer any medical reason to decline a prenatal test for Down Syndrome (Suciu). Prenatal genetic testing has always engendered controversy, but the topic has recently inserted itself into discussion again due to this new blood test drastically altering the nature of the debate by transforming prenatal testing for Down Syndrome into a safe and effective procedure. It is here that the ethical dilemma rears its head; we are trapped between a desire to provide women with the most information possible regarding their pregnancies and to acknowledge concerns regarding the rights of the fetus, as the only solution in the case of a positive test is the termination of the pregnancy. The lack of treatment for Down Syndrome means that while many consider the practice of prenatal testing an advancement in healthcare on the one hand, others fear that the practice violates the rights of the fetus and perpetuates ableist attitudes that suggest that only rational life is worth living. When this issue is considered, a woman’s right to know may seem to promote the stigmatization of and discrimination against those with disabilities. This paper will focus on the ethics of prenatal testing for Down Syndrome in the context of the novel risk-free test, examining whether the test is ethically permissible and whether it should be a standard procedure in our current prenatal

care regimen.

In this paper, I will show that the arguments in the literature positioned against prenatal testing for Down Syndrome are reducible to two main arguments, one of which is deontological and the other teleological, neither of which is morally persuasive. These arguments secure moral impermissibility of the test in the ends of the action or in its means, respectively. After examining both arguments and the responses to them, I will demonstrate that we are morally obligated to present this test to all pregnant women in the early stages of their pregnancies and encourage them to take it, although any woman who wishes to opt out of the procedure may do so. Not only should NIPT testing be offered to all, but it should also be an aspect of prenatal care that is subsidized by the government and incorporated into our prenatal testing battery. For this process to be ethical, however, true autonomy must be maintained through complete freedom of information. If we desire to uphold the right to liberty to which each person is entitled, we have the moral obligation to provide complete information and counseling that is non-coercive to parents of fetuses who test positive for Down Syndrome. This means that all women who receive positive tests must have access to subsequent nondirective counseling that thoroughly and clearly explains the reality of raising a child who has Down Syndrome. This is conducive to the mental, physical, and emotional well-being of all children, and will ensure their best lives and proper care above all else. In the section that follows, I will present what the diagnosis of Down Syndrome entails, as well as provide a brief overview regarding the prenatal testing options that are currently available. Next, I will discuss arguments in the literature that stand in opposition to prenatal testing for Down Syndrome and discuss how arguments in favor of testing oppose these points. Finally, I will demonstrate why I stand in favor of prenatal testing for Down Syndrome by examining both circumstances in which a test takes place: a negative diagnosis and a positive diagnosis followed by nondirective counseling. In a utilitarian fashion, I will examine the distribution of pleasure and pain for the parents and the fetus in each circumstance in order to support my assertion.

Down Syndrome and Prenatal Testing

Trisomy 21—more commonly referred to as Down Syndrome—is the most prevalent chromosomal defect found in live-born babies and is caused by an additional erroneous 21st chromosome that supplements the usual pair (Dixon 8). The syndrome is compatible with life, and those diagnosed with

it can live for decades. However, as a result of the diagnosis, those with Down Syndrome will suffer from a deficit to normal mental functioning, which may be accompanied by physical abnormalities such as low muscle tone, small mouth and ears, flat nose, and excessive skin in some facial areas (8). It is impossible to determine the individual's degree of mental impairment prenatally, as it ranges vastly from mild to severe, the latter of which can result in an IQ as low as 20 (9). Down Syndrome also places individuals at a significantly heightened risk for congenital heart defects, hearing loss, severe refractive errors, and obstructive sleep apnea, as well as at a slightly heightened risk for leukemia, Hirschsprung's disease, hip dislocation, and thyroid disease (9). The tremendous variance in the severity of the syndrome means that instantiations of it can range from chronically debilitating or mosaic. The former severely impedes an individual's development and renders them incapable of living independently, while the latter is less physically impactful and involves fewer health and learning difficulties due to fewer cells being involved.

Advancements in prenatal screening for Down Syndrome have allowed parents to discover the presence of Trisomy 21 in their offspring prior to the birth of the child, which is especially useful to pregnant women over the age of 35, who are at a heightened risk of carrying fetuses with chromosomal abnormalities (18). While the prevalence of Down Syndrome is approximately 1 in every 1300 infants at age 25, by the time a woman reaches 35, the probability has skyrocketed to one in 365—more than triple the chance from a decade prior (Jotkowitz). By the time a woman is 45, the odds become 1 in 30 (Jotkowitz). Until recently, the two primary methods by which fetuses were tested for Down Syndrome were amniocentesis and chorionic villus sampling (CVS), both of which are invasive and pose a risk of miscarriage, albeit miniscule (Dixon 11). Amniocentesis, performed around week 20 of pregnancy, uses skin cells from the fetus to conduct a chromosomal test; the procedure is conducted by inserting a needle into the uterus to collect a sample of amniotic fluid, and the associated risk of spontaneously miscarrying falls between 0.5% and 1% (Dixon 11). CVS, which is performed earlier in the pregnancy, is performed by collecting placental tissue which is collected via a catheter tube inserted into the vaginal canal (12). Not only is CVS invasive, but it also carries an additional 0.5% to 1% risk of miscarriage over amniocentesis (12). Despite these slim probabilities, many pregnant women do not undergo testing in fear of losing their babies.

It is for this reason—among many others—

that non-invasive prenatal testing (NIPT) has been considered an incredibly promising method of trophoblast-derived scanning for chromosomal abnormalities. In contrast to amniocentesis and CVS, NIPT uses cell-free DNA—namely, fragments released into plasma from routine maternal cell turnover—to determine the fetal genotype (Harraway). This means that there is no risk of spontaneous abortion of the fetus, making the test immensely preferable to amniocentesis and CVS. The blood test can also be performed at any point from the tenth week of pregnancy onward, making it a more immediate option than either of the invasive tests. Additionally, the test is incredibly precise, offering a 99% detection rate and a mere 0.1% chance of a false positive as opposed to the 85-90% detection rate and 4-5% chance of a false positive offered by other prenatal tests (Harraway). NIPT, in short, offers an easy, early, and risk-free way to discover with near certainty whether the fetus will be born with Down Syndrome.

When a positive test is received, women make the decision to abort approximately 50% to 60% of the time, with the remainder of mothers keeping the child or placing them up for adoption¹ (Dixon). Pregnancy termination rates after receipt of a positive test can vary drastically due to its dependence on a wide variety of factors, from women's economic situations to their religious beliefs. One of the largest current problems in the clinical application of NIPT is the associated financial cost. The test is rarely covered by health insurance and can be financially burdensome, restricting many women's access to it; in Australia, for example, NIPT costs between \$400 and \$500 (Harraway).

Another fear that accompanies the spread of NIPT is that of coercion. Due to the power dynamic that exists between doctor and patient, there is the risk that women will feel pressured to conduct NIPT against their will, or even be pushed in the direction of aborting the fetus upon receipt of a positive test. This risk is especially prevalent for women in marginalized groups, as they are more vulnerable to coercion from medical professionals. Discrimination against individuals with Down Syndrome continues to exist within the medical profession, and parents often report that the “prenatal counseling they received was aggressively directive” rather than nondirective (McCabe). Misinformation among doctors often leads them to supply parents with false information

¹ This statistic has been hotly contested, as I have encountered abortion rates ranging from 50% to 90% in the literature I have read. While an article in *The New York Times* has cited the rate at 90%, the rate was based on a single research study rather than an overview and is therefore likely too high. Genetic counselor Elizabeth Balkite has drawn upon her experience to estimate a termination rate of 60%, while geneticist Dr. Ellen Wright Clayton cites a rate of about 50% (Dixon). After reading a wide variety of literature, I believe the actual rate of pregnancy termination upon receipt of a positive test falls between 50% and 60%.

regarding the syndrome, such as when one mother in the early 2000s was told that the life expectancy of her child with Down Syndrome would be three years, when it was in fact over 50 years (McCabe). This is not an isolated incident, as many women in the Netherlands decided to abort their fetuses with Down Syndrome due to physicians being unaware of recent advances in medicine; over 90% feared that their child would never be independent, 90% believed that the abnormality would be too severe, and over 80% believed that the burden would be too heavy for them, the child, and their families to bear (McCabe). This coercion may be caused by economic factors, with insurers emphasizing to women that if they carry a child with Down Syndrome, they will be entirely financially responsible for any future costs the child may procure (McCabe). This leads many women in disadvantaged economic situations to abort due to an inability to financially support their child with Down Syndrome.

Understandably, there has been insurmountable concern and backlash against the NIPT procedure and subsequent upward trend in the abortion of fetuses that are likely to be born with Down Syndrome. In fact, the number of articles found in the PubMed database regarding prenatal testing for Down Syndrome has increased tremendously in recent decades; between 1980 and 2000, fewer than 2,000 articles were published. In the two decades that followed, nearly 4,000 papers have surfaced regarding the prenatal diagnosis of Down Syndrome.² Much of the reception of NIPT has been critically negative – members of the disability rights movement condemn genetic testing, claiming that it is nothing but a “search and destroy mission” that will decrease societal tolerance for disabilities (Dixon 21). Some have even gone so far as to equate the abortion of disabled fetuses with institutionalized eugenics.

Arguments For and Against Prenatal Testing for Down Syndrome

The most common argument mounted against prenatal genetic testing for Down Syndrome provides the foundation for the disability rights movement: it is that genetic testing is solely performed “because a value judgment has been made that there is merit in identifying a fetus who could become a person with a disability” (Dixon 12). Testing is often done with the intent of identifying a chromosomal defect in the fetus so that it may be aborted.

² I conducted this search on the PubMed database on April 22, 2021, using the combined search terms “Down Syndrome” AND “prenatal”. The search turned up 1,923 results between the years 1980 and 2000. Between the years 2000 and 2020, there were 3,663 results. This search was intended to demonstrate the dramatic recent uptick in scholarly articles due to advancements in prenatal genetic testing technology and heightened controversy over the novel plasma test.

This argument—dubbed the “reductivism” argument—operates on the fear that prenatal testing will lead to the “identification of all persons with their selectable traits” (15) as opposed to their personhood and the dignity they are imbued by nature of being people. Each individual is worth infinitely more than the mere sum of their parts, and the identification of an individual with a single trait he possesses would lead to the loss of our “sense of humanity” (15) and cause us to view individuals with shared traits as interchangeable. We must always view the person first and maintain their dignity by respecting them for their entire identity, of which disability is only a part.

Furthermore, due to the societal prejudice against the disabled, prenatal testing is “morally problematic” (13) due to the perpetuation of “discriminatory attitudes about both impairments and those who carry them” (13). Renate Lindeman, a mother of two children with Down Syndrome, corroborates this view by explaining that “singling out a condition by offering routine screening... sends a strong value judgment about potential quality of life” (Lindeman). This value judgment sends a painful message to members of the disabled community that their lives are worth less than those of able-bodied individuals. Dixon goes so far as to say that opting for prenatal testing fosters “eugenic attitudes that individuals with some disabilities are properly excludable, not only from society, but also from existence” (Dixon 13). Put simply by bioethicist Adrienne Asch, “Do not disparage the lives of existing and future disabled people by trying to screen for and prevent the birth of babies with their characteristics” (13). This perspective makes the test incredibly ableist, deeming rationality as the determining factor in whether or not a life is worth living. Accompanying this argument is geneticist Francis Collins’ notion that the normalization of genetic testing and subsequent abortion “might eventually lead to abortion for merely undesirable characteristics, such as gender” (Glover). He, among others, fears that discrimination based on ability will lead to a slippery slope in which parents will test for undesirable traits in their progeny and abort them should the traits appear. There would be nothing to stop decisions about abortion from made based on gender, race, ethnicity, or sexual orientation—all factors that could be considered undesirable due to societal prejudice and discrimination.

The reductivism argument, focused on the integral nature of personhood and dignity, appears to be heavily influenced by the work of the moral philosopher Immanuel Kant, who explains that we must “act so that [we] treat humanity, whether in [our] own person or in that of another, always as an

end and never as a means only” (Kant 429). Kant’s ethics are deontological, or duty-based, so it is the act in and of itself as opposed to the act’s outcome that is significant. According to Kant, rational beings are classified as persons in the moral sense, making them ends in themselves. This means that they are deserving of dignity and respect as whole persons and cannot be used only as a means to obtain some other end. Reductivism argues that by conducting prenatal genetic testing, one is reducing a person to their ability status and therefore using them as a means of obtaining one’s desired offspring. Rather than seeing a child with Down Syndrome as merely their diagnosis, we must see them as a person with dignity and worthy of respect. Many find this argument to be fundamentally flawed, arguing that Down Syndrome is a trait that impacts the person in every aspect of their personhood, from their mental capacity to their capability to live independently and physical abilities. Testing for Down Syndrome is not a reduction of a person to a single trait, but an identification of a chronic condition that a person and their caretakers will face their whole lives.

Utilitarian bioethicist Peter Singer argues that the practice of prenatal diagnosis of fetuses with Down Syndrome is “as it should be” (Singer 187). While Down Syndrome does impact a person in all aspects of their life, it does not make their life not worth living, he claims. Rather, he argues that fetuses are interchangeable, making the abortion of a disabled fetus with the intent of replacing it with an abled fetus morally acceptable. The mother rejects one potential child in favor of another. The aborted fetus losing its life “is outweighed by the gain of a better life for the normal child who will be conceived only if the disabled one dies” (Singer 188). Many proponents of the test also claim that while it is possible for people with Down Syndrome to live long and happy lives, it would be better to live a life as an able-minded and able-bodied individual. It is preferable to be abled rather than disabled. This is not to say that disabled lives are not worth living, but rather that a value judgment can be made; we know that ability is preferable. Given the choice between mental impairment and full cognitive function, would any of us select to be mentally impaired? Would we willingly choose to be at greater risk for a host of conditions? Furthermore, if there was a potential treatment for Down Syndrome, proponents of prenatal testing argue that a substantial number of parents would opt into treatment for their children. Acceptance of the treatment is a clear indication that Down Syndrome is not mere atypical functioning, but rather an aberration that hinders flourishing. Parents who would opt for treatment make a clear value judgment: it would be better were their child abled. If

it were just as preferable to be disabled as it were to be able, we would say nothing to women drinking and smoking while pregnant. We advise women against these actions, however, because we know that ability is preferable. Prenatal testing for Down Syndrome notifies parents about the future pain their child may suffer—a critical aspect of their child’s life—and allows them to select a fetus that is abled over a fetus that is disabled.

This is not, of course, a denial of the dignity and respect that is owed to each disabled person. We can still hold immense respect for those who are disabled and simultaneously hold the belief that ability is inherently preferable. Take, for example, legal measures to prevent accidents that cause paraplegia. These measures do not deny the dignity of current paraplegics, nor do they harm them in their personhood. They simply seek to prevent future suffering from occurring. The desire to prevent future paraplegia is rooted in this same assertion—ability is preferable—yet does not harm those who suffer from paraplegia.

Similarly, prenatal testing that allows parents to avoid the birth of children with Down Syndrome is not a targeted attack on those with Down Syndrome in their personhood. Testing is not an action done with the intent to hurt others or deny their dignity but to inform parents and allow them to make an informed decision regarding their future with the fetus. It is unjust to parents and potential future lives to deny them the ability to test for Down Syndrome, as current pain that may be felt by the disabled due to heightened testing is no adequate justification for preventing women from obtaining the most information possible regarding their pregnancies. If the widespread use of prenatal genetic testing is insulting to the disabled community, that pain does not justify halting testing and medical progress.

Consider yet another example: the drug thalidomide, when consumed by pregnant women to mitigate morning sickness, led fetuses to be born without any arms or legs. The drug was taken off the market immediately once this was discovered, and parents of children affected by the drug were compensated (Singer 189). If these children were merely different but lived otherwise equal lives to an abled person, compensation would not have been awarded. Was it unfair to the children born limbless as a result of this drug to take the drug off the market once its side effects were discovered? No. It is not disrespectful to take the drug off the market, nor does it deny the dignity of those who lack limbs. Instead, it is because we undoubtedly know that it is better to have limbs than to not have limbs. The current pain

of the disabled community regarding prenatal genetic testing is not enough to put an end to prenatal testing.

In response to the claim that selection based on ability could potentially lead to selection based on other traits such as gender, proponents of the test claim other traits in a child are not comparable to Down Syndrome. As Singer explains, this ability preference cannot be likened to racism or sexism. While it may certainly be the truth that being a heterosexual, white male would furnish a child with the easiest life in our society, that may not be the case in every society. In the case of Down Syndrome, on the other hand, there may be suffering involved regardless of the societal conditions, whether it be mental impairment or increased risk for other conditions. Testing fetuses for Down Syndrome and allowing the parents to make an informed decision would ensure that they are as knowledgeable as possible about the future of their child.

The second, largely teleological argument in opposition to prenatal testing for Down Syndrome focuses on society at large, claiming that those with disabilities will be greatly socially disadvantaged as a result of prenatal genetic testing. Social divisions primarily stem from the identification of individuals with a single trait—in this case, disability—with the desire to affix a label to and direct hatred towards a group. The primary disadvantages that the disabled face, disability rights advocates explain, stem mainly from a negative societal view as opposed to the disability itself. Testing with the intent to reduce the prevalence of Down Syndrome in the population does nothing but exacerbate justifications for social division and discrimination against those who are disabled. An intentional reduction in the disabled population propagates the idea that those who are disabled should not exist, furthering discrimination and intolerance against the disabled community. In the words of Lindeman, “Progress that was made over many generations, in terms of inclusion and equal rights, could be lost in less than one” (Lindeman).

Furthermore, the political effectiveness of the disabled community is limited by virtue of their reduced numbers. There are fewer of them who are capable of using their voices to advocate for change and reform, which will lead to little social motivation to continue developing technology and providing services to benefit those with disabilities. Finally, society may suffer a loss as a result of genetic testing identifying fetuses with Down Syndrome. Collins asserts that testing with the intent to abort fetuses with Down Syndrome could potentially lead to the loss of “persons who might ultimately be of great value to society” (Glover).

This second argument is markedly consequentialist, as it deems prenatal testing for Down Syndrome morally reprehensible based on its societal outcome. Those in favor of testing remain unconvinced, however, since attempting to reduce the suffering intrinsic to disability does not equate with the message that those who are disabled should not exist. They are dignified persons worthy of respect, and any person who uses disability as a reason to discriminate against those with Down Syndrome has committed an injustice against them. It is desirable that the disability be eradicated in order to prevent suffering; it is not that case that those with Down Syndrome are less human or less worthy of living. No one has the authority to say that an individual deserves hatred or injustice due to being disabled. As Peter Singer explains, his position does not imply that it would be better that those with disabilities did not exist, but rather that “parents of such infants should be able to make [the decision to abort]” (Singer 189). This is not adequate justification, he continues, to reject the interests of those who are disabled on account of their disabilities. We must continue to show respect for those who live with disabilities in the present.

It is also not the case that prenatal testing will drastically reduce the disabled population and decrease its political effectiveness, even though it may lead to a decrease in the Down Syndrome population. There already exist—and will remain—resources in place in order to ensure that the needs of those who are disabled are met. Those resources will certainly not be withdrawn with an increase in prenatal genetic testing for Down Syndrome. Not to mention, an increase in prenatal genetic testing and subsequent abortions will never eliminate Down Syndrome entirely. Parents are not mandated to abort the fetus as a result of a positive test; many may feel as though parenting a child with Down Syndrome would be fruitful and worthwhile. Even if Down Syndrome were eliminated, there remains a tremendous number of persons comprising the disabled community, as those who have Down Syndrome make up only a small percentage of all those with disabilities. The disabled community would retain its political voice even in the most extreme of circumstances. If all disabilities could be detected and eradicated prenatally, there would still be an overwhelming number of persons who would become disabled later in their lifetimes and represent the disabled community politically.

In response to Collins, while it is certainly possible for those with Down Syndrome to live long, happy, and satisfying lives, those in favor of NIPT testing respond that “Society will not likely lose any scientists, doctors, lawyers, or presidents as a result of genetic

testing revealing Down syndrome” (Glover). They may have a wonderful and warm impact on their families and the people surrounding them, but due to the mental impairment that those with Down Syndrome suffer, their presence or absence will likely not have a tremendous impact on society as a whole.

A Reanalysis of the Down Syndrome Testing Debate

Having addressed the largest objections regarding prenatal genetic testing for Down Syndrome and their counterarguments, I will begin my justification for offering the test to all pregnant women and covering the cost of it with a simple assertion: a genetic test does not carry with it any inherent evil. The test is rather good in itself, because it grants the child’s parents information about the fetus that the woman carries and grants autonomy to the couple. Many arguments that vehemently oppose prenatal genetic testing subscribe to the idea that conducting a test will guarantee an abortion. This is far from the truth. Even if the test result is positive, it is simply not the truth that parents will make the decision to abort the fetus in every instance.

The controversy surrounding the test is difficult to sidestep because both sides raise critical points—while information regarding a woman’s pregnancy is critical, the test can have the tendency to perpetuate ableist ideas and attitudes in society. While it may be true that it is preferable to be abled rather than disabled, human flourishing is not strictly defined by the physical and the rational. These two opposing sides indicate that the test has been somewhat misconceived. While the test itself is good insofar as it provides information, it is unethical to simply provide the test without subsequent nondirective counseling if a positive result is received. Abortions performed after receipt of a positive test are not necessarily a result of ableism or the desire to have an abled child; instead, many couples may be afraid of the impact the child that is to come will have on their lives. If the couple does not have full understanding of the diagnosis, they will not be able to make a truly autonomous decision. It restricts a couple’s autonomy and liberty to simply provide them the test and allow them to make a decision without offering any counseling, as the couple needs adequate and full information in order to make a truly free decision. It is for this reason that medical professionals must be trained with adequate, balanced, and up-to-date information, and counseling services must be respectful and standardized. They must present all the available information regarding Down Syndrome and what life with a child who has Down Syndrome

will realistically look like. They should be sensitive and compassionate, providing as much information as they have available. For instance, they should provide the contact information of parents who have children with Down Syndrome for reference. This is especially important considering that a survey of American Congress of Obstetricians and Gynecologists Fellows conducted within the last decade indicated that although 95% of responders offered prenatal testing for Down Syndrome to all women, 40% of them believed their training for screening and diagnosis to be “less than adequate” (McCabe). This demonstrates the need to ensure that physicians are provided with correct information and properly trained so as not to influence a mother’s decision. The only way to ensure that we respect the couple’s autonomy is through this unbiased counseling, which allows the couple to make a choice completely. This training will help eliminate ableist views from medical practice and from society at large and, at the same time, provide the mother with as much information as possible regarding her pregnancy and respecting her right to determine her future with the fetus.

The success of nondirective counseling can be demonstrated through the California Prenatal Screening Program, which seeks to make prenatal screening for Down Syndrome available to all women in the state (Flessel). Founded in 1986, its mission is to allow women to make informed decisions regarding their pregnancies. Women are capable of participating or opting out of the program (Flessel). Nondirective counseling services are offered upon receipt of a positive test result, with medical professionals following established guidelines that allow women to make a wide array of informed choices. The medical professionals involved ensure that Down Syndrome is never misrepresented in the rhetoric utilized to counsel the mothers, making the practice useful, accurate, and ethical.

With this new addendum to the NIPT procedure, offering the test becomes morally obligatory because it truly allows the parents to make the best, most informed decision for their future with the fetus. This decision will ultimately lead to the maximization of the pleasure and the minimization of the pain for both the parents and the fetus. This utilitarian approach is based on the ethics of John Stewart Mill, who believes that the ends of an action are what make it right. Mill explains that actions are right “in proportion as they tend to promote happiness; wrong as they tend to produce the reverse of happiness” (Mill 7). An action that follows this rule is in accordance with Mill’s Greatest Happiness Principle: it produces the greatest good for the greatest number, with the good being

defined as happiness, or the presence of pleasure and the absence of pain. This approach holds power in its equality, impartiality, and universality. We will arrive at the validity of my assertion by examining the parents’, fetus’, and society’s best interests regarding each of the test’s possible outcomes: either the test is negative and the pregnancy continues, or the test is positive and followed up by nondirective genetic counseling.

The first outcome is the simplest and morally unproblematic—the parents know that there is an overwhelming likelihood that their child will not have Down Syndrome, the child’s life was not risked in order to conduct the test, and the mother carries the baby to term. This ultimately results in the maximization of pleasure and the reduction of pain for both parties. The test was incredibly useful in providing the future parents with a critical piece of information that would have changed both their lives and their child’s life forever, and due to the foreknowledge they now have, they are capable of more adequately preparing for the birth of their child.

A positive test and immediate decision to carry the fetus to term demonstrates the importance and the utility of the test most apparently. When parents know their child will have Down Syndrome and select to carry the fetus to term, they are able to emotionally and financially prepare for the heightened needs of a child with Down Syndrome. They will be able to conduct research and prepare themselves prior to the birth of the child, answering questions about what they will need to do differently from most parents to provide adequate care for their child as well as how the child will impact them personally. Parents will learn that their child will be mentally impaired as well as at a heightened risk for certain conditions, and, knowing that their child will have mental capacities that fall below that of a child with full cognitive ability, will adjust their expectations accordingly. This will allow the child with Down Syndrome to flourish within the context of their disability, as their parents will not have unrealistic expectations for what they are capable of. Parents will also plan accordingly and ensure that they can support the child for their whole life—if need be—and undergo medical costs associated with conditions that may accompany their diagnosis. Children with Down Syndrome born in this circumstance are infinitely better off than their counterparts with non-informed parents, demonstrating the importance and power that the prenatal test holds. Since the parents of these children are prepared on all fronts to welcome them into the world, their presence is genuinely desired, and they will likely never have to fear that their parents do not have the resources and

the capacity to care for them. This foreknowledge is very clearly conducive to the maximization of pleasure of the child and their parents, and despite the intrinsic pain that accompanies the child's disability, it will be minimized due to the parents' proper research and planning regarding how to best meet the special needs of their child. The counseling provided will further aid the parents in planning for the birth of their child.

The final scenario is ultimately the most controversial and the reason that many condemn prenatal testing as morally unacceptable. This is because upon receipt of the test, the parents may be inclined to perform an abortion. I believe, however, that upon implementation of nondirective counseling that accurately portrays life involving a child with Down Syndrome, parents will realize how fulfilling raising their child can be and feel as though they are prepared to do so. This makes counseling crucial; it shows the disabled community, those in medicine, parents-to-be, and society that disabled lives are worth living and can be incredibly fulfilling. This accurate nondirective counseling may very well lead to a decrease in the rate of abortions upon receipt of a positive test, as it will portray the reality of the syndrome accurately and allow the parents to make the most informed decision possible. Even in the case of the ultimate abortion of the child, however, the test and subsequent counseling bring about the greatest good. It is important to recall that every situation has "its own medical, social, and emotional complexities that the moralist has to factor into his or her decision making" (Jotkowitz). A multitude of explanations can be provided as to why parents make the ultimate decision to abort: they may have insufficient financial resources to properly care for a child with Down Syndrome, they may not have the time and attention to provide necessary care, or they may not be able to emotionally cope with the decreased capabilities of their child. In this case, the parents make a choice that leads to their greatest possible happiness and do so with full autonomy. The counseling they are provided does not force them to abort their child, but rather, enlightens them about the reality of raising a child with Down Syndrome and allows them to make a well-informed decision, keeping their liberty intact. No one involved perpetuates ableist beliefs, because the parents and physician have access to an abundance of accurate, current information. The decision is ultimately up to the parents, but the test is undeniably performed ethically with the desire to produce the greatest possible happiness for all involved. It follows that in each of these circumstances, paying for NIPT and nondirective counseling allows for the greatest good to be accomplished for all, regardless of the

outcome of the test and subsequent decisions regarding the future of the pregnancy.

Some claim that the decision to abort is in the best interests of the fetus as well. In order to justify this, they may claim that the fetus will not experience any pain in its lifetime if aborted, because it will have never been given the chance to exist and experience suffering in the world. This avoidance of suffering entirely is greatly preferable to a situation in which the fetus was never tested and born to parents who would have selected to abort had they known the child would have Down Syndrome. In this case, the child's suffering may be amplified significantly. Not only would the child have to bear the burdens accompanying his disability, but there may be additional suffering associated with the possibility that the child's parents did not want a child with Down Syndrome. They may fail to provide them with the care they deserve or not treat them properly due to their failure to live up to the expectations they hold for their children, although it is no fault of their own. It is possible that parents could warm up to them and embrace the challenges they bring, but if they would have aborted with the knowledge of a positive test result, they may also resent their child and desire that he had never been born. In cases like these—in which parents would have avoided giving birth to a child with Down Syndrome given the choice—it would have been better had the child never been born. This argument is difficult to justify however, when one considers that abortion not only eliminates the possibility for pain of the future child, but the possibility for any pleasure as well.

One could counter the argument in favor of government subsidization of NIPT by claiming that prenatal genetic testing for Down Syndrome is a waste of money and that there are other issues that require funding even more; that money could even go to programs to support those who are living with Down Syndrome instead. Since the testing is still novel and expensive to conduct, one could argue that it is certainly not a critical aspect of prenatal care that should be paid for, especially since its cost is burdensome on society. Everyone would have to contribute to ensure access to these tests for only a few to reap the benefits. This argument fails, however, because a price cannot possibly be ascribed to a procedure that ultimately benefits society, leading to the dissemination of accurate information regarding Down Syndrome and the disabled community in general. This will cultivate a greater environment of acceptance and knowledge in which those who are disabled are better understood by all in society—especially medical professionals and those in government, who greatly impact the lives

of disabled people—and can more easily flourish. This testing and counseling may even lead to greater funding being allocated to disability research, which could reduce healthcare costs in the long run. With further exploration into NIPT, we could come to learn more about Down Syndrome and derive preventative measures for many of the associated health risks, ultimately reducing healthcare and service costs.

Conclusion

In this paper, I have demonstrated the importance of non-invasive prenatal testing for Down Syndrome and explained why it, along with nondirective genetic counseling, should be a mandatory and paid-for aspect of prenatal care. In every circumstance, conducting the test leads to the best outcome for both the child with Down Syndrome, their caretakers, and society, which should be our ultimate goal in conducting this testing. There is much at stake regarding this testing, as its widespread distribution could prove to be incredibly beneficial for pregnant women who want to be able to make informed decisions regarding their future children as well as those in medicine, who will eradicate their misconceptions regarding Down Syndrome. This will halt the perpetuation of ableism as well as ensure that medical professionals have accurate information about the diagnosis. If NIPT testing becomes more widespread, we must go about the implementation of it carefully, ensuring that couples do not feel pressured to decide one way or another by their obstetrician-gynecologist. We must set standards for testing and counseling so that the autonomy of the parents is never compromised, as the practice will quickly become immoral if couples are encouraged to take action that goes against their own judgement upon the receipt of a possible test.

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