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# ACMG MAGAZINE

~ THE HBS WAY ~  
SOC GEN 108  
UCLA

SELECTIVE  
ABORTION  
OF  
DISABILITY

ALEX//CHIAMAKA  
MISAKI//GRACE



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# Notes from the Writers



## Misaki Kobayashi

*I am a 4th year Human Biology and Genetics major, focusing on public health and medicine. As a student who is interested in working as a medical professional in the future, the topic of this magazine, selective abortion of disability, was a complex yet intriguing topic to explore. It was my pleasure to create this magazine with my amazing, passionate team members - Chiamaka, Grace and Alex. Thank you to Professor Kelty and the TAs for helping us bring this magazine to life! I hope this magazine will give you insight into disability-selective abortion and various perspectives surrounding its controversy. Enjoy!*



## Chiamaka Nwadike

*Chiamaka Nwadike is a 4th year in the institute of Society and Genetics. My work examines social phenomena from an anti racist, intersectional feminist, class conscious framework. I enjoy writing and creating with multimedia platforms. Working on this project definitely made me realize that my feminist values can definitely be at the opposition of many different frameworks but working on this project strengthened my beliefs and made me read more into how frameworks impact our point of understanding different issues.*

# Notes from the Writers



## Alex Shambayate

*I am a 4th year Human Biology and Society major and working on this project strengthened my understanding of how biological and social issues are always intertwined. From creating this idea and sharing it with my classmates to the production of this magazine, working on this project has definitely been enlightening to work through from beginning to end. Thank you to Professor Kelty and our TA Zia for all the hard work and providing us the space to create a project like this and have the conversations necessary to expand our minds. Thank you to my group members and my family for all the support needed to pull this project off. Hope you all enjoy.*



## Grace Yang

*I am a 4th year, Human Biology and Society major. I've really enjoyed this quarter in Soc Gen 108! I love project-based classes and writing so I think this course combined the many reasons I chose the Human Biology and Society major. Throughout the process of putting together this magazine, I was able to get to know my fellow peers and explore the many facets that makes HBS so unique. A large part of this course was focusing on one particular issue within our community and researching the different lenses and perspectives that makes this issue controversial. I hope that this magazine and our articles can help expand a little more about selective abortion and human disabilities. A large thank you to Professor Kelty and the TAs for being so flexible and understanding throughout the course, especially near the end of the quarter amidst the grad student strike and the COVID-19 pandemic. Thank you so very much!*



# Abortion Techniques in the United States

Presented by Misaki Kobayashi



**BE INFORMED:** abortion

**JUST FACTS.**

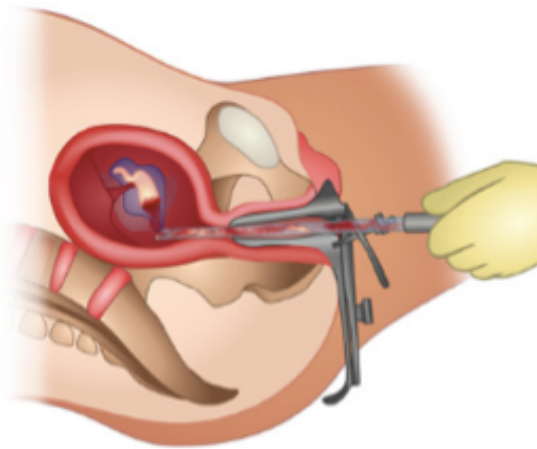
## MEDICATION ABORTION

**Medication abortion** is a method used to terminate a pregnancy using combination of medications, mifepristone followed by misoprostol. This method can be used from 49 days to 70 days (10 weeks) gestation. Mifepristone is a progesterone receptor antagonist that inhibits the activity of endogenous or exogenous progesterone by competing with progesterone at its receptor site. By inhibiting the progesterone activity, it initiates the breakdown of the lining layer of the uterus and implanted embryo. Misoprostol then causes uterine contractions and cervical ripening, which expel the embryo through vagina. Its common side effects include cramping, pain, and bleeding, which are similar to the symptoms of miscarriage. Complications, such as hospitalization and infection after medication abortion is rare and occurs in no more than a fraction of a percent of patients and there is no evidence that specific types of facilities are needed to ensure the safety of medical abortion. Indeed, most women return home after taking mifepristone and take the misoprostol 28 to 24 hours later. (The National Academies Press, 2018, P.51-55) Although this method is minimally invasive, it is not effective after women undergo prenatal screenings for genetic anomalies, such as Down syndrome, as those prenatal screenings cannot be done before 10 weeks of gestation (UCSF Health, 2019).

[NEXT PAGE](#)

[More on Abortion techniques](#)

## Vacuum Aspiration



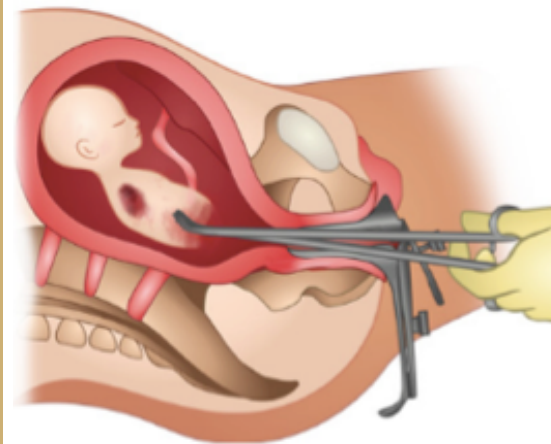
# ASPIRATION ABORTION/VACUUM ASPIRATION

**Aspiration Abortion/Vacuum aspiration** is the most common abortion method used in the United States regardless of gestation, accounting for 68% of abortion in 2013. It is a minimally invasive procedure and typically takes less than 10 minutes to complete and is slightly more effective than medication abortion. The method may be used up to 14 to 16 weeks gestation, and is also used to manage incomplete medication abortion and miscarriage. The first step of aspiration abortion is to dilate the cervix using tapered mechanical dilators so that the contents of the uterus can be expelled. After cervical dilation, a suction cannula (plastic or metal tube) is inserted through the cervix into the uterus. The cannula is attached to a vacuum source; either electric vacuum pump for electric vacuum aspiration or a handheld, hand-activated aspirator for manual vacuum aspiration – to empty the uterine contents. (The National Academies Press, 2018, p.59) The fetus is torn into pieces as he/she is pulled through the hose (Surgical Abortion Methods). Ultra-sound is used for guidance is sometimes used. Aspiration abortion rarely results in complications. However, as in medication abortion, bleeding, uterine pain, and cramping are expected as its side effects. (The National Academies Press, 2018, p.60)

## DILATION AND EVACUATION

Dilation and Evacuation method, or D&E method, is sometimes referred to as a second-trimester surgical abortion and appear to account for the majority of abortion procedures performed between 14 and 20 weeks gestation. The procedure is typically performed in two stages – the first step is cervical preparation, dilating the cervix with dilator and/or prostaglandin (e.g., misoprostol). Once dilation is adequate and sedation or anesthesia has been administered, the amniotic fluid is aspirated. If D&E is performed before 16 weeks gestation, suction aspiration may suffice to empty the uterus. After 16 weeks, forceps is used to remove fetal parts and the placenta. (The National Academies Press, 2018, p.62) In order to remove the fetus from uterus, the abortionist must snap fetus' spine and crush her/his skull (Surgical Abortion Methods). Since this procedure is more invasive compared to medical abortion or aspiration abortion, patients are observed following the procedure to monitor for any postoperative complications. Although D&E can be effective with minimal rates of complications, ranging from 0.05 to 4 percent, one study has found that women with two or more prior cesarean section had sevenfold increased risk of a major complication (i.e., transfusion required; disseminated intravascular coagulation; or a reoperation involving uterine artery embolization, laparoscopy, or laparotomy;) (The National Academies Press, 2018, p.62-63).

## Dilation and Evacuation (D&E)



## Induction or Prostaglandin



## INDUCTION ABORTION

Induction Abortion is nonsurgical abortion that uses medications to induce labor and delivery of the fetus. This method can be used up to 3rd/final trimester of pregnancy. Saline or urea is injected induce fetal demise, then Digoxin or potassium chloride is injected to ensure fetal demise (Surgical Abortion Methods). The combination of mifepristone and misoprostol (as described in medical abortion technique) are then typically used to induce labor in order to remove fetus. The expected side effects include cramping, pain, and bleeding, as well as nausea, vomiting, diarrhea, chills, and headache (The National Academies Press, 2018, p.66-67). The gestational parameters for induction vary depending on the facility, patient and provider, preference, and state laws and regulations. California sets its gestational parameters for induction as "fetal viability" (States with Gestational Limits for Abortion, 2020). "Fetal viability means "having reached such a stage of development as to be capable of living, under normal conditions, outside the uterus," however, there is no universal gestational age that defines viability (GH, 2001, p.49). Therefore, gestational parameters for induction still remain unclear.



# ~ Interview ~

Presented by Misaki Kobayashi

We had a privilege to interview **Karen Saito** (pseudonym), thirty-seven years old, who is a survivor of cervical cancer. She and her husband do not have children because cervical cancer that she suffered in her early 30's made it very difficult for her to bear a child. Although she was/is not directly affected by the disability-selective abortion controversy, she is one of many women who are unable to have children of their own despite their desire to have one.

*If you are able to have one child without any reproductive complication, would you bring him/her to term? Would you undergo prenatal screenings to check if the fetus has any genetic anomalies?*

Yes, I always loved kids and I would love to have one if possible. And to answer your second question, I am not really familiar with prenatal screenings – like how much they cost and where I can get them – but I would be open to it if it's accessible.

*Would your answer (regarding bringing the fetus to term) change if you find out that he/she has Down syndrome during your pregnancy?*

I do not want mean to be cruel at all – but I would strongly consider terminating the pregnancy if I find out that the fetus has Down syndrome. I am not confident that I will be able to raise a child with such disability. I know the ideal answer is “I would have the baby no matter what” – but the reality is, it is not easy. It would already be hard enough, both physically and financially, to raise a healthy child for us.



We both work full-time and we are exhausted by the time we come home. To add on that, I don't think my family (parents and siblings) would support the idea of bringing the fetus to term if we all know that he/she will be born mentally disabled. They all know it's not easy and there is still discrimination against people with disabilities in this country. I do not see myself having a child with special needs while working full-time and receiving no support from my family. Not only that, I think I would feel almost depressed bringing the fetus to term knowing he/she has condition that lasts lifetime and is not curable. Again, I want to emphasize that I have nothing against children with Down syndrome or other disabilities. I love children. What I am saying is that it is not realistic for me and my husband to take care of a child with disabilities considering various factors, such as our financial status and family support.

## ~ Thoughts ~

This interview gave us valuable insights into perspectives of women, who wish to have children but are/were not able to, on raising a child with disability and selective abortion of disabilities. While it is easy to solely blame women who choose to abort fetuses with disabilities, claiming that they are cruel for ending a life, it is important to listen and pay closer attention to women's perspectives on raising children with disabilities – how taxing it is for a woman to raise a child with disability in our society today? Do we, as society, support women and children with disabilities enough to criticize them if women choose abortion?



# Birth Defects

## So, what are birth defects?

Birth defects are critical conditions that affect approximately 1 in 33 babies born in the United States every year.

## What factors increase the risks of having a baby with birth defects?

People who may have increased risks in having children with birth defects include those who:

- Are older in age
- Have a personal/family history of birth defects
- Have previously had a child with birth defects
- Use certain medications around the time of conception and throughout pregnancy
- Have a medical condition such as diabetes mellitus or obesity
- Use recreational drugs or drink alcohol during pregnancy

## What causes birth defects?

Some birth defects are passed down genetically from parent to child. Other birth defects are caused by chromosomal problems during the fetal stages. A small number of birth defects are caused by exposure during a woman's pregnancy to certain medications, chemicals, and even infections. For many cases, the cause is unknown.

## Risks of pregnancy over age 30

In the United States, birth rates for women in their 30s are at the highest levels in four decades due to women waiting to have children later in life. However, an older mother may be at increased risk for things such as:

- Miscarriages
- Birth defects
- Twins
- High blood pressure
- Gestational diabetes
- Difficulties during labor



# PRO-LIFE

"Pro-life" is the argument that the government has an obligation to preserve all human life, regardless of intent, viability, or quality-of-life concerns. The Roman Catholic Church proposes a pro-life ethic that prohibits:

- Abortions
- Euthanasia and assisted suicide
- The death penalty
- War, with very few exceptions

In certain cases when the pro-life ethic conflicts with personal autonomy (e.g. abortions and assisted suicide), it is considered conservative. Whereas, in cases when the pro-life ethic conflicts with government policies (e.g. the death penalty and war), it is considered liberal.

# PRO-CHOICE

"Pro-choice" is the argument that individuals have unlimited autonomy when it comes to their own reproductive systems, as long as it does not intrude on the autonomy of others.

Under the Partial Birth Abortion Ban passed by Congress and signed into law in 2003, abortion became illegal under most circumstances in the second trimester of pregnancy, even if the mother's health is in danger. Individual states have their own laws, some banning abortion after 20 weeks and most restricting late-term abortions.

Pro-choice is not simply "pro-abortion" because people who are pro-choice want to ensure that all choices remain legal for people to decide what is best for them.

# THE IN-BETWEEN

For people who say they are neither pro-life or pro-choice, what are their stances? Three-fourths of Americans want to keep the landmark *Roe v. Wade* Supreme Court ruling that made abortions legal in the United States, but a large majority also wants to put restrictions on who, when, and why people can get abortions. Some people may see strong opinions for both pro-life and pro-choice supporters which has resulted in them deciding on yes, abortions should be legal, but in order to conserve resources and also encourage the public to make informed decisions when it comes to abortions, there should be restrictions in place.

#### Sources:

<https://www.thoughtco.com/pro-life-vs-pro-choice-721108>

<https://abortion.procon.org/>

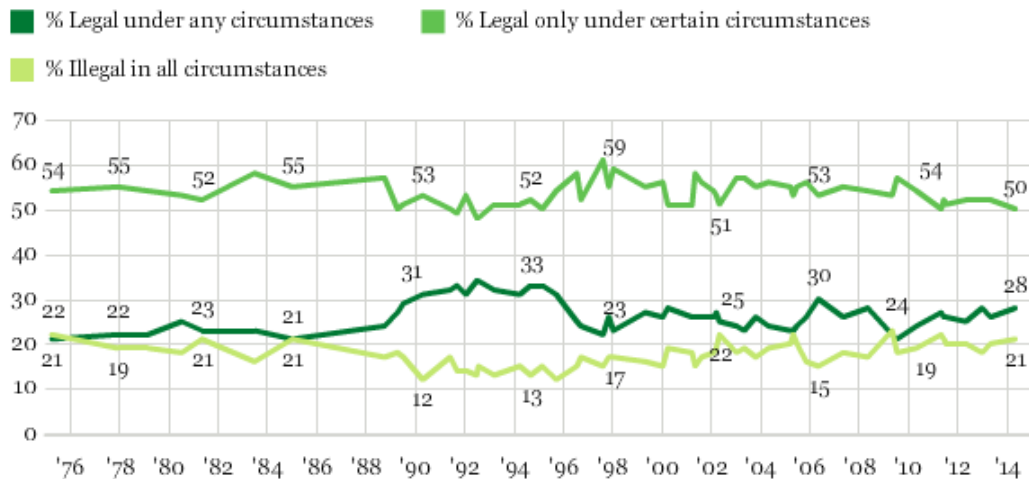
<https://news.gallup.com/poll/244709/pro-choice-pro-life-2018-demographic-tables.aspx>

# Abortions and How America Votes

50% of U.S. adults say abortion should be "legal only under certain circumstances," favoring limited abortion rights. 28% say abortion should be legal in all circumstances and 21% believe it should be illegal in all circumstances.

## *Degree to Which Abortion Should Be Legal*

Do you think abortions should be legal under any circumstances, legal only under certain circumstances, or illegal in all circumstances?



Values are shown for dates closest to election in midterm election years.

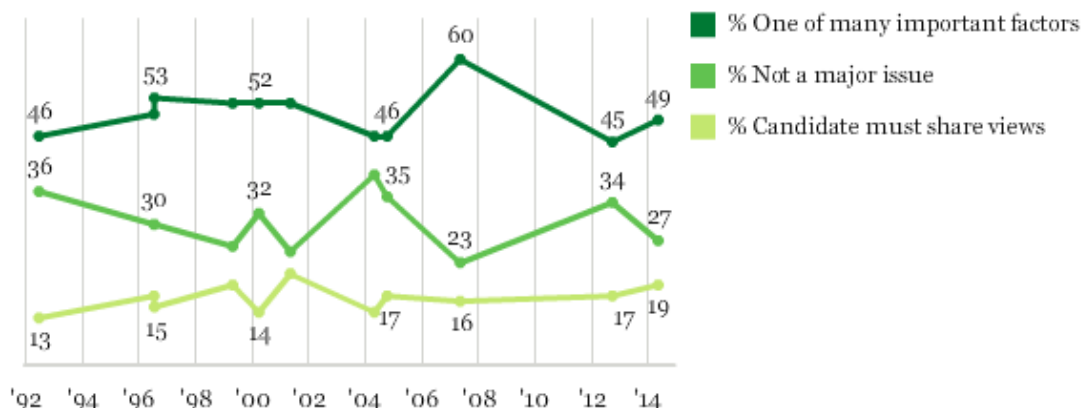
Note: The trend includes two polls conducted by Gallup/Newsweek: January 1985 and July 1992.

GALLUP

19% of U.S. registered voters currently say candidates for major offices must share their views on abortion to get their vote.

## *Impact of Abortion Issue on Vote for Major Offices*

Thinking about how the abortion issue might affect your vote for major offices, would you [only vote for a candidate who shares your views on abortion, (or) consider a candidate's position on abortion as just one of many important factors, (or) not see abortion as a major issue]?



Based on registered voters

GALLUP



## Landmark Abortion Cases

1971

UNITED STATES V. VUITCH

First abortion case to reach Supreme Court. "Health" should be understood to include considerations of psychological as well as physical well-being.

1973

ROE V. WADE

This case challenged a Texas law prohibiting all but lifesaving abortions. The Supreme Court invalidated the law on the ground that the constitutional right to privacy encompasses a woman's decision whether or not to terminate her pregnancy.

1975

BIGELOW V. VIRGINIA

Supreme Court ruled that states could not ban advertising by abortion clinics. Such bans violate the First Amendment's guarantees of freedom of speech and freedom of the press.

1979

BELLOTTI V. BAIRD

All minors must have the opportunity to approach a court for authorization to have an abortion, without first seeking the consent of their parents, and that these alternative proceedings must be confidential and expeditious

1980

HARRIS V. MCRAE

In *Harris v. McRae*, the Supreme Court rejected a challenge to the Hyde Amendment, banning the use of federal Medicaid funds for abortion except when the life of the woman would be endangered by carrying the pregnancy to term.

2007

GONZALES V.  
CARHART AND GONZALES V.  
PLANNED PARENTHOOD  
FEDERATION OF AMERICA,  
INC. (CARHART II)

Justice Kennedy held that in the face of "medical uncertainty" lawmakers could overrule a doctor's medical judgment and that the "State's interest in promoting respect for human life at all stages in the pregnancy" could outweigh a woman's interest in protecting her health.

1986

THORNBURGH V. AMERICAN  
COLLEGE OF OBSTETRICIANS  
AND GYNECOLOGISTS

Supreme Court struck down a provision of a Pennsylvania statute requiring doctors to use abortion techniques that maximized the chance of fetal survival, even when such techniques increased the medical risks to the pregnant woman's life or health.

2016

WHOLE WOMAN'S HEALTH  
V. HELLERSTEDT

U.S. Supreme Court ruled that two abortion restrictions in Texas are unconstitutional because they would shut down most clinics in the state and cause Texans an "undue burden" to access safe, legal abortion.





# Biological Lens of Disability

There are various ways of viewing a disability. It can be viewed through a social lens, cultural lens, and predominantly through a medical lens. Here we will be discussing three disabilities: Down Syndrome, Tay Sachs and Hard of Hearing/Deaf. The commonality between all three of these disabilities is that they are congenital (present from birth), incurable, and can be detected through prenatal genetic testing. Down Syndrome is a chromosomal disorder that is coupled with intellectual disability, characteristic facial features (such as upturned eyes, flattened face, a short neck to name a few) and weak body muscle tension (Shapiro 4). Down Syndrome involves some sort of mutation to Chromosome 21. There are three types of chromosomal changes that can result in Down Syndrome. The most common type occurring in 95% of people who have Down Syndrome is that of having an extra Chromosome 21. The other two types are more rare occurring at a frequency of 2-3%. Down Syndrome can arise through translocation, in which part of Chromosome 21 becomes attached to another chromosome. The final type of Down Syndrome is mosaicism, in which extra genetic material of Chromosome 21 attaches to other cells in the body. The chances of giving birth to a child with Down Syndrome increases with maternal age. The older a woman is, the more likely the homologous chromosomes will not separate properly through cell division through what is known as nondisjunction. Statistically speaking, women who are of age 45 and older have a 1 in 45 chance of having a child with Down Syndrome (Shapiro 7). Another type of congenital disorder that we will be focusing on is Tay-Sachs disease. The occurrence of this disorder is very rare as it presents in an autosomal recessive way. This fatal condition arises through having both copies of the HEXA gene in each cell have a mutation. Because of such mutation in the HEXA gene, there is consequential absence of the enzyme B-N-acetylhexosaminidase A. This mutation in gene and acid result in a deadly build up of the ganglioside GM2 lipids (Milunsky 3). This results in a profound mental and motor deterioration. Infants who are diagnosed with this neurological disease die by the ages of two to four. The other disability that we will be focusing on is being Deaf or Hard-Of-Hearing. Being Deaf or Hard Of Hearing is characterized as the inability for the ear to convert vibrational energy into neural impulses (Grundfast 5). This disability can be congenital, hereditary (meaning caused by an affected gene), progressive, and or acquired. For the sake of this article, we will be primarily focusing on the congenital occurrence of this disability. The result of being Hard-Of-Hearing can come from either having autosomal dominant genes, autosomal recessive genes, or through X-linked transmission. There are multiple genes that come into play with being Deaf, as well over 200 different syndromes that are linked

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Milunsky, Aubrey. "Prenatal Diagnosis Of Tay-Sachs Disease." *The Lancet*, vol. 302, no. 7843, 1973, p. 1442., doi:10.1016/s0140-6736(73)92836-5.  
Grundfast, K. "Genetics and Hearing Impairment." *Genes, Hearing, and Deafness*, 2007, pp. 1-1., doi:10.1201/b13986-2.



# 

Abortions, though controversial, are common throughout the United States. According to the “Abortion Incidence and Service Availability in the United States 2017”, ever since 2014, one in every five pregnancies are terminated through the means of an abortion (Jones 4). In 1973, the Roe v. Wade court case granted women the constitutional right to terminate their pregnancy for any reason before the fetus is considered viable. In 1992, Planned Parenthood of Southeastern Pennsylvania v Casey put in place that states cannot impose abortion laws that are too burdensome for women; this case, however, this case also allowed states to place restrictions on abortion during the first trimester (Reingold 7). Because of this implementation, the great downfall of this procedure is its lack of uniformity in services throughout the country. In most states, abortion is legal and abortion clinics are still available, however, in Midwest and Southern states bans against abortion have been instituted in aims to lessen the occurrences of abortion. Unfortunately, 57% of women who seek an abortion are from these said hostile state environments. The number of clinics that provide abortions has decreased to 6%, with 22% in Midwest and 13% in the South, however, the need for abortions is still the same (Jones 3). Because of such bans, women either have to travel to other states or undergo unsafe procedures themselves. For example, 21% and 16% of women in the South and the Midwest respectively tried to self-terminate their pregnancy because they did not have the the means or resources in their state to go to a medical professional. In 95% of states women are able to receive an abortion no later than after the 8th week of gestation and 34% allow for abortion up until the 20th week (Jones 9). In some of the restricting states the time frame is shortened to even six weeks, which is when a heartbeat can be detected. Prenatal testing or screening can also be done early on during the pregnancy. In most cases you can receive such genetic information as early as nine to ten weeks, however the longer the gestation period the more accurate such conclusions can be drawn. If states place bans on longer abortion gestation, then women are more likely to prematurely abort a child if they have reason to believe their child will be born with a mental or physical disorder. The cost of an abortion also increases the longer the gestation is. On average, an abortion costs around \$300-500 during a 10 week gestation and the price doubles to \$1000-1500 if an abortion is done during the second trimester (Jerman 5 ). Women who have to travel to other states gamble much more financial risk due to travel fares. The majority of women who do seek an abortion are poor or low income (Jarman 3). The factors of gestation, price and travel can compound and result in greater financial issues. If a low income women does not have enough money to pay for an abortion, she may need more time to collect necessary funds; however, the longer she waits the further along her gestation increases as well as the price of a later abortion. The current circumstances around abortion policies are disproportionally varying from each state to state. This in turn affects almost all women who seek an abortion, especially women of color as well as financially vulnerable women.

### 

Jones, Rachel K. “Abortion Incidence and Service Availability in the United States, 2017.” Guttmacher Institute, 4 Feb. 2020. [www.guttmacher.org/report/abortion-incidence-service-availability-us-2017](http://www.guttmacher.org/report/abortion-incidence-service-availability-us-2017).  
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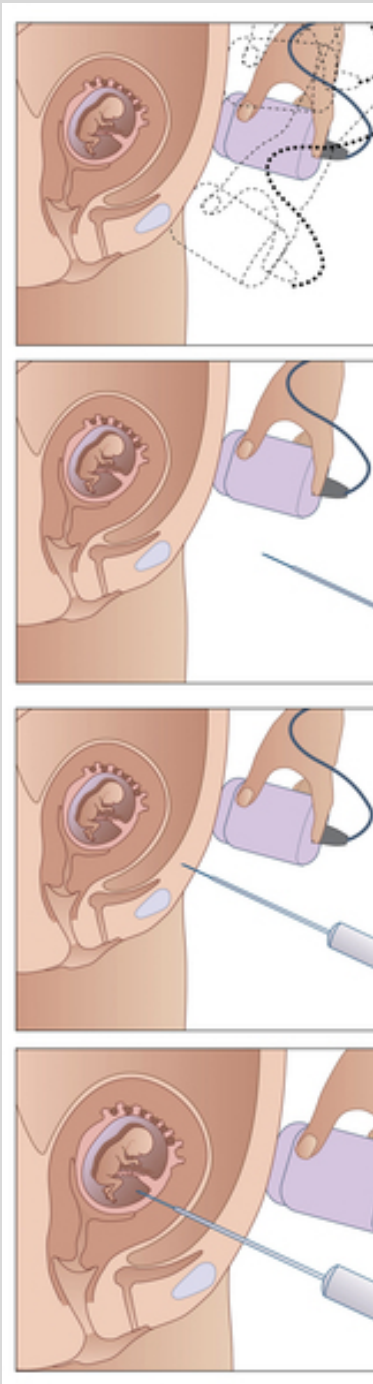
# Correlation Between Selective Abortions and Prenatal Screening Technology and Process

## History and Technology of Prenatal Screening

Prenatal screening has evolved over time to become a more non-invasive approach to testing the fetal genome for various conditions. According to the American College of Medical Genetics and Genomics (ACMG), pre-natal screening methods must be carefully modified to minimize harm to the fetus and mother if it is expected to become incorporated routinely in medical care (Gregg, Thompson et. al, 1). Previously, pre-natal screening was done during the second trimester of pregnancy but advancements in “chorionic villus sampling” (Gregg, Thompson et. al, 1) allows for testing to be done during the second trimester of pregnancy. In addition, developments in noninvasive pre-natal screening techniques has allowed for “cell-free fetal DNA sequences to be isolated from a maternal blood sample” (Gregg, Thompson et al, 1). This noninvasive strategy has also been used to screen for gender in the past since the maternal blood sample holds ~10% of the fetal product. However, statistics show that more invasive strategies such as amniocentesis or chronic villus sampling (Gregg, Thompson et al, 2) provides a more definitive answer for diagnosis and decreased false positives in testing.

There are two main types of prenatal tests: prenatal screenings and prenatal diagnostics. Prenatal screenings do not identify genetic diseases but are able to detect certain chromosomal abnormalities. Prenatal diagnostics however can detect genetic conditions or birth defects. Diagnostic tests can determine with 99.9% accuracy and certain conditions must be specifically tested for and accuracy and vary depending on the test that is ordered. (Genetic Alliance 2009) Today, Noninvasive Pre-natal Screening/Testing (NIPS/T) include “sex chromosome aneuploidy screening for selected copy-number variants...laboratories are encouraged to meet the needs of provides and their patients by delivering meaningful screening reports” (Gregg, Thompson et al 1). These tests have come a long way from the invasive methods that were primarily used such as diagnostic tests that reveal certain disorders by testing “placenta obtained through amniocentesis” (American College of Obstetricians and Gynecologists). That form of testing is the more invasive process when amniotic fluid is taken from the uterus for testing via a needle that is injected into the sac that holds the fetus.

## Correlation Between Screening and Abortion?



To understand a possible correlation between the prenatal screening process and its link to selective abortion rates, we must first understand the prenatal screening process and information is generally provided to patients. Firstly, it is important to understand that the information that is provided to patients is critical to the choices that they make after they've received information from the laboratories or providers. Data concerning termination rates with prenatal diagnosis is difficult to obtain because the United States does not track national registries, but using information gathered from the British Isles Network of Congenital Anomaly Registers, there are more terminations (5215) than live births (4288) of children with Down Syndrome (Bradford 2015). Using this information along with estimates of live births of fetuses with Down Syndrome in 2010, Bradford was able to deduce that selective abortion after prenatal diagnosis of Down Syndrome has reduced 30% since 2011 in the United States. However, there is an identifiable correlation between selective abortion and fetuses that are diagnosed with Down Syndrome.

Despite the decrease in termination over time, there is still a high correlation between prenatal screening and abortion. Doctors are not required to provide information to parents regarding how to deal with the results that are mailed to them. Pamphlets that provide information on conditions such as Down Syndrome or Cystic Fibrosis are not required to be in doctor's offices. In addition, parents are just left to make decisions to terminate without access to accurate and educational information regarding the conditions that are tested for. This can lead to already preconceived stigma surrounding the conditions to proliferate and contribute to the decision to terminate. According to Bradford's study concerning the

termination of pregnancies of fetuses with Down Syndrome, 61% of Asian/Pacific Islander groups who test for Down Syndrome are likely to terminate and are among the highest number of terminations (Bradford 2015). While the lowest number of terminations is among the Native demographic with 16% of them choosing to abort fetuses tested for Down Syndrome (Bradford 2015). These statistics help us understand that stigma concerning conditions such as Down Syndrome is present in various communities but especially in Asian communities and white communities as they are present at the highest rates of termination. This correlation between termination of pregnancy can be tied back to the prenatal screening process as we can see that high levels of termination can be present due to lack of information provided during the prenatal screening process.



# Eugenics and Prenatal Screenings



Understanding how eugenics operates systematically is crucial framework from which to understand the selective abortion of disabilities. Firstly, eugenics is historically understood to be reproducing with the goal of working towards a more “advantageous” society with only positive, more desired traits selected for within the human population. Eugenics, when paired with white supremacy, produces ideology that places white-centric features as the more desired features, while features that are nonwhite are not desired and placed lower in a hierarchical organization of society. We see this reproduce itself in the form of concentration camps in Germany, harmful white beauty standards globally, and the development of white supremacy as an institution.

Eugenics when paired with ableism, produces the idea of a ‘norm’ with cognitive and physical ability. Those who do not have these abilities

such as walking or speaking without impairment are considered undesirable. These traits are not only desired but are organized as a norm, a baseline for which social and environmental infrastructure is organized. For example, stairs leading up to a door way is considered the ‘normal’ way for people to enter a building while those who cannot utilize stairs are given ramps that are often placed at the margins of the building and are hard to navigate. This is just one example of the way ableism plays a role in how our physical environments are designed to suit those who have the desired physical ability of using stairs. There are many other examples of how ableism is structured on an organized level to prevent those who do not have ‘desired abilities’ but for now, we will focus on the conditions for which are highly selected for in terms of terminating a pregnancy after a prenatal screening. As mentioned, Down Syndrome, Tay Sachs Disease, and Cystic Fibrosis are the conditions that are likely to be terminated against after prenatal screenings. When viewing

these terminations through a eugenics lens, it is clear that there is a desired way of being in terms of ability and we see those traits selected for whenever termination is chosen for fetuses tested for specific conditions.

Stigma against disabled people does not remain in a theoretical realm; rather, it is evident in the way beauty standards are constructed, environmental infrastructure, and our beliefs on productivity and value. Many of our sociological beliefs that define who is a “contributing and productive member of society” are heavily influenced by ableist values. These values then infiltrate our ideas and beliefs on who deserves a chance to live after prenatal screenings. According to a study conducted by Digital Commons at University of Nebraska, 28.9% of respondents believed that people with Down Syndrome should not work or go to school because they are distracting. In addition, 30% of people believed that people with Down Syndrome should not work at all. These statistics are just examples of the stigma surrounding people with Down Syndrome and are a reflection of the kind of ideology of what is considered a desirable person and how this impacts our view of them in the work place, school environment, and other public spaces.

Because ableism infiltrates social infrastructure and is found within our dominant beliefs surrounding disabled people, these beliefs are also found in the process of prenatal screenings and diagnostic testing. Eugenics is found in the prenatal screening process and we can see that selective abortion of disabilities when coupled with the stigma and dominant beliefs surrounding disabled people’s contributions to our society, one can come to the conclusion that these selective abortions play into the eugenics ideology of who we find valuable and desirable in our society. At the root of eugenics is ableism. The idea that people who have traits deemed undesirable under specific systems such as white supremacy or capitalism is found within ableism as well. These ableist ideologies infiltrate

the prenatal screening process and contributes to the high rates of termination once prenatal screenings are done. This is eugenics in practice because we, as a society, had decided that disabled people, particularly those with Down Syndrome or Cystic Fibrosis are not worthy or desirable. Fetuses with no complications are not selected against and this sends a message that those without ‘abnormalities’ are the desired and are more likely to be carried to term.

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# The Larger Questions: How Disability Rights and Reproductive Justice Impact Each Other



## What is disability?

~ Medical model of disability vs. Socially constructed disability ~

According to Centers of Disease Control and Prevention (CDC), a disability is “any condition of the body or mind (\*impairment) that makes it more difficult for the person with the condition to do certain activities (\*activity limitation) and interact with the world around them (\*participation restrictions).” They are many types of disabilities such as those that affect individuals’ vision, movement, thinking, remembering, learning, communicating, hearing, mental health, and social relationships (CDC, Disability and Health Overview, 2019). \*Impairment in a person’s body structure or function, or mental functioning; examples of impairments include loss of a limb, loss of vision or memory loss. \*Activity limitation, such as difficulty seeing, hearing, walking, or problem solving. \*Participation restrictions in normal daily

activities, such as working, engaging in social and recreational activities, and obtaining health care and preventive services. (CDC, Disability and Health Overview, 2019).

However, there is no universal definition or understanding of disability. We will explore two models of disability – the medical model and the social model – to better understand what disability is.

**The medical model** of disability identifies people’s problems mainly with their impairments. According to Alderson, the predominantly medical model focuses on Down syndrome and emphasizes negative views of this “most common form of severe mental retardation” linked to “precocious dementia of the Alzheimer type.” The medical model regards Down syndrome as a fixed, factual, physical and mental state, and its associated pathologies as the main or sole cause of morbidity and

mortality in people with the condition. Some pediatric texts mention Down syndrome only in reference to prenatal screening and/or emphasize severe pathology as if all individuals with Down syndrome are adversely affected. Despite high incidence of heart defects, no one with Down syndrome in the UK has yet received heart transplant, as clinicians believe the shorter life expectancy of people with Down syndrome as an obstacle to be qualified for an organ transplant. When Down syndrome is regarded as extremely disabling and not treatable, abortion is viewed as the only medical remedy. A study shows that most midwives support universal prenatal screening for Down syndrome and prospect of having a child whose prognosis with such condition is deemed very bleak by conventional medical opinion (Alderson, 2001, p.361-365). Definition of disability formed by Centers of Disease Control and Prevention, therefore, fits the medical model of disability as it focuses on individuals' physical and/or mental inability to perform certain activities and fails to consider societal impacts when defining a disability.

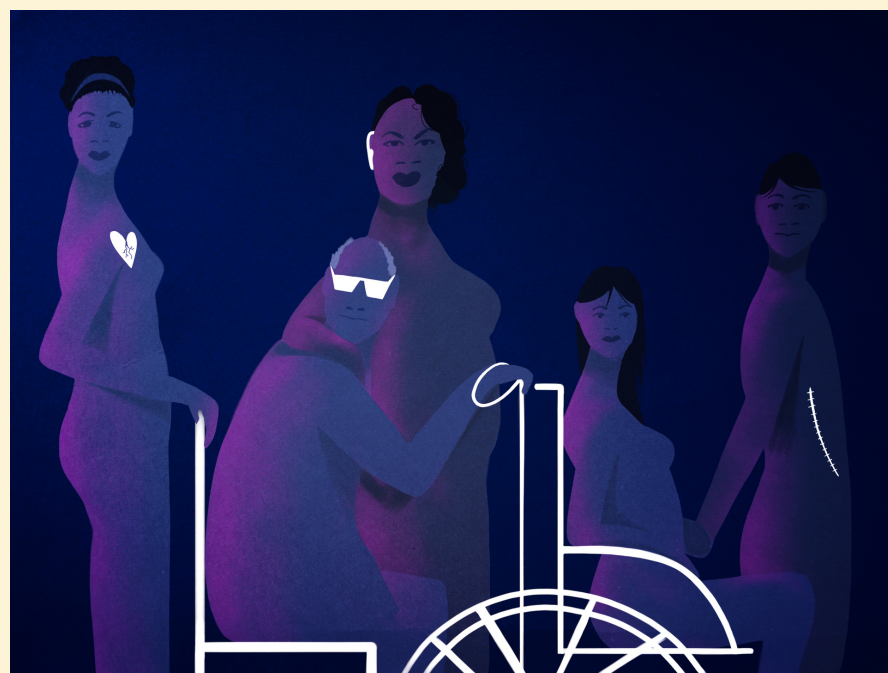
Furthermore, some conditions like Tay-Sachs disease are commonly considered as disability due to the severity of \*impairment,\*activity limitation, and/or \*Participation restrictions without the consideration of societal influence. Bertha Alvarez Manninen, professor at Arizona State University, states that the disease is "fatal, often within four of five years from birth, and the road to death is fraught with intense physical suffering, including deafness, blindness, loss of muscle strength, delayed mental skills, loss of motor skills, seizures, and paralysis of muscle function." And aborting a sick fetus in order to spare the child this kind of life need not manifest indecency or viciousness – "Quite the contrary, it can often manifest feelings of concern, care, and love." (Manninen, 2015)

**The social model** of disability attributes the problems people experience mainly to disabling social barriers and negative attitudes that unnecessarily exclude them from mainstream society.



While the medical model recognize disability as a fixed, factual, physical, and pathological state, the social model recognizes social effects on disability – The social model argues that societies make choices on whether or not to give treatment for impairment and individuals' health and well-being are strongly influenced by societal values and choices. A study of 280 infants with Down syndrome attributed their poor health to a lack of "necessary care" by parents and professionals. Surveys also suggest that individuals with Down syndrome are considered less worthy of health care because of their lower intelligence. Denying treatment to children because of their shorter life expectancy contributes to reducing their life span, creating a vicious cycle. Some researchers are concerned about prenatal screening promoting the stigmatization and intolerance against individuals with disability, which is a major cause of the suffering experienced by affected individuals and their family members, and such screening may not be helpful to the society. (Alderson, 2001, p.361-366) Adrienne Asch, PhD, MS, for example, argues that the difficulties facing disabled persons are often times due to "discriminatory social arrangements that are changeable," rather than an inherent difficulty in the condition itself. He warns professionals should "reexamine





negative assumptions about the quality of life with prenatally detectable impairments and should reform clinical practice and public policy to improve informed decision making and genuine reproductive choice.” According to Asch, current data on children and families affected by disabilities indicate that disability does not preclude a satisfying life. Therefore, he calls for public health professionals to change the inadequate social arrangements that construct disability in our society (Asch, 1999, 1649-1654). In addition, conditions including deafness have been viewed as disability for decades. The medical model considers deafness as impairment - the inability to hear interferes with a person’s ability to respond to environmental cues and to communicate. However, an emerging proponent of deafness as a culture asserts that deafness is a socially constructed disability and therefore does not need to be “fixed.” According to Jones from Center on Disability Studies, this proponent claims that stigma, language, and prejudice have contributed to the formation of the deaf as minority group, labeling deafness as “disability” (2002, p51-60).

### ~Social model of disability in a film ~

*A World Without Down Syndrome?* is a documentary film about Down syndrome and ethics of prenatal screenings, fronted by Sally Phillips. Driven by the experience of raising her son Olly, who has Down's syndrome, Sally explores some of the ethical implications of our nationa

l screening policy. She interviews scientists and people with Down syndrome, and investigates a thorny subject that begs questions relevant to us all: what sort of world do we want to live in and who do we want in it? Phillips argues against the prenatal screenings for Down syndrome, as she does not view the condition as “disability” and see no necessity in finding out such condition in fetus. She advocates for the social model of disability in this film by emphasizing the societal role in creating/constructing a disability.

## The Philosophy Behind Abortions

### Moral personhood

What is “human life” and how does one define when life begins for a fetus after conception? One definition is straight-forward and biological, human life means a member of the human species, one who has human DNA. Another definition includes aspects that make human life that includes characteristics giving that being the ability to think, communicate, and has moral rights. What is the role of philosophy on the modern abortion debate? Patrick Lee According to Patrick Lee, author of “A Christian Philosopher's View of Recent Directions in the Abortion Debate,” he argues that in staying true to the teachings of Pope John Paul II and previous popes, he argues for the pro-life position as a Christian philosopher. Lee states that at conception, there is a distinct, whole, although immature, human being that has full moral value and worth. As parents, the mother and father have obligations and responsibilities to not abort the child. The three points Lee makes are as follows:

1. A human embryo is a full human being because its DNA is separate from either of its mother’s or father’s. Its homeostatic

1. operations (those that exist to help keep the embryo alive) is also separate from its mother's or father's, especially distinct from the processes that keep the mother alive
2. The embryo is a human organism, and as such, has human genetic makeup because it is produced by humans.
3. The new human embryo is a whole human being, possessing the internal resources needed to actively develop himself or herself to full maturity. The human embryo is fully capable of surviving and maturing unless deprived of a suitable environment or by accident or disease.

### Don Marquis

Don Marquis, a Professor of Philosophy at the University of Kansas, also has some ideas to add to this pro-life argument that human embryos are indeed whole human beings. Marquis defends that, except in unusual circumstances, abortion is seriously wrong. This is his argument: Fetuses are both human and alive. Humans have the right to life. Therefore, fetuses have the right to life. Of course, women have the right to control their own bodies, but the right to life overrides the right of a woman to control her own body. Therefore, abortion is wrong. Marquis further argues the anti-abortion syllogism. It is usually attacked by attacking its major premise: the claim that whatever is biologically human has the right to life. This premise is subject to scope problems because the class of the biologically human includes too much: human cancer-cell cultures are biologically human, but they do not have the right to life. Moreover, this premise also is subject to moral-relevance problems: the connection between the biological and the moral is merely assumed. It is hard to think of a good argument for such a connection. If one wishes to consider the category of "human" a moral category, as some people find it



plausible to do in other contexts, then one is left with no way of showing that the fetus is fully human without begging the question. Thus, the classic anti-abortion argument appears subject to fatal difficulties. These difficulties with the classic anti-abortion argument are well known and thought by many to be conclusive. The symmetrical difficulties with the classic pro-choice syllogism are not as well recognized. The pro-choice syllogism can be attacked by attacking its major premise: Only persons have the right to life. This premise is subject to scope problems because the class of persons includes too little: infants, the severely retarded, and some of the mentally ill seem to fall outside the class of persons as the supporter of choice understands the concept. Marquis concludes that abortion deprives fetuses of a "future like ours", and therefore, abortion is wrong. This argument is based on an account of the wrongness of killing that is a result of our considered judgment of the nature of the misfortune of premature death.

### Judith Thomson

Judith Thomson, in *Philosophy & Public Affairs*, Vol. 1, no. 1 (Fall 1971), argues on the defense of abortion, stating that the fetus is not a person from the moment of conception. A newly fertilized ovum, a newly implanted clump of cells, is no more a person than an acorn is an oak tree. She argues that opponents of abortion commonly spend most

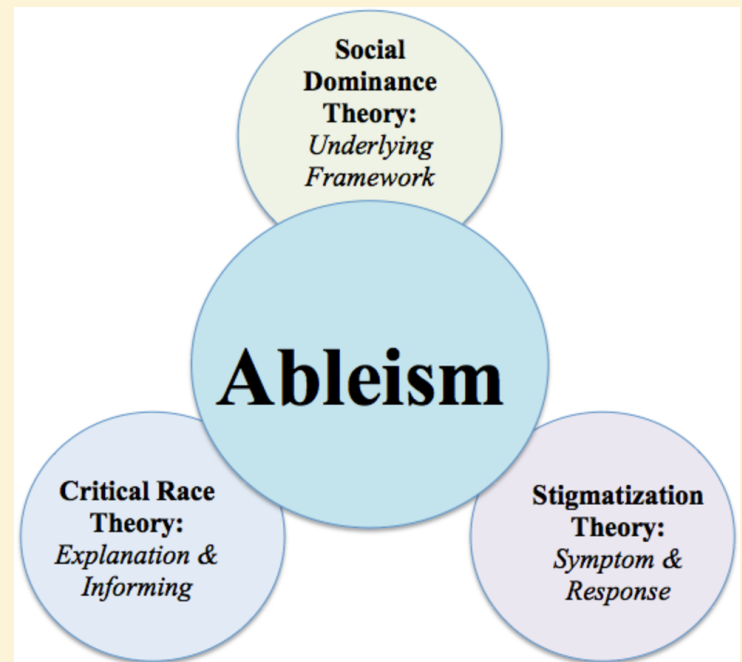
of their time establishing that the fetus is a person, and hardly anytime explaining the step from there to the impermissibility of abortion.

One of Thomson's famous examples in support of bodily autonomy is the famous unconscious violinist. If you were the only person able to help the violinist, it would still not be morally right to force you to give up your bodily autonomy in order to save the violinist. In the case of rape, Thomson argues that for the question of whether you have a right to life at all, or how much of it you have, it shouldn't turn on the question of whether or not you are a product of a rape. And in fact the people who oppose abortion on the ground she mentioned do not make this distinction, and hence do not make an exception in case of rape. She concludes that a very early abortion is surely not the killing of a person, and that is why abortions should be allowed.

### David Boonin

David Boonin, a Professor of Philosophy and the Director of the Center for Values and Social Policy at the University of Colorado in his book *Beyond Roe: Why Abortion Should be Legal-- Even if the Fetus is a Person* argues that

although the fetus is a person and does have a right to life, abortion should still be legal. Boonin discusses the legal precedent: *McFall v. Shimp*, and argues that having a right to life does not give a person the right to use another person's body, even if they need to use that person's body to go on living as is the case with a woman who is carrying a human embryo. Boonin continues to posit the bodily autonomy that should be given to people who may choose to keep their unborn child, but it is also their right to abort should they deem that the best scenario. Boonin maintains his pro-choice stance that no one else should decide what a woman does with her body and unborn child than the woman herself.



### What is Ableism:

Ableism is used in terms of a disability scope. This type of oppression discriminates against those who are considered "less able" than able-bodied individuals in society. Ableism reflects negative labeling and treatment of those who have a disability (CITE). This type of "-ism" makes it seem as though there are some abilities that are desirable and if you do not have said desirability you are subject to ableist narratives. Society has a preference for typicality and normative mental and physical characteristics on the human body. This form of discrimination furthers the medical narrative stating that those who are disabled have something fundamentally wrong with themselves and need to be "fixed" to be seen as desirable by others in society. There seems to be no room for those who are different or vary in some way or another from a "normal" individual. Ableism results in unfair treatment of those who have a disability (Wolbring 1). The ableist narrative is further strengthened through science and technology. The use of such advancement allows for the monitoring of desirable traits and intervention resulting in the detection of traits that are unfit for the normalcy of society. The direction in which we are moving in will only further perpetuate ableist ideals (Wolbring 3) Selective abortion is a form of ableism against fetuses who



may have a life with a disability. In many cases, women who are informed that they will give birth to a child that has a birth defect will terminate their pregnancy and possibly “try again” in hopes of potentially giving birth to a child that does not have any defects. This shows how deep this issue runs and how such societal institutions dominate the lives of current and potential beings.

In some cases a disability can be seen as a culture rather than as a disability. Individuals who are a part of the Deaf community, for example, do not view being Deaf as a disability. Rather, the Deaf community has created a language and entire culture around being Deaf. An act of ableism towards the Deaf community is the innovation of the cochlear implant. This device makes it seem as though those who are deaf “lack” hearing abilities and therefore need to hear in order to better fit into society; people who do not hear have to be “fixed” because something is wrong with them. The cochlear implant does not take into consideration the fact that someone may want to be Deaf and may want to be a part of the Deaf community. The device is supreme to the wants of those who are considered as being disabled in the eyes of normative individuals. Ableism is deeply ingrained in the everyday world. For example, buildings that do not have ramps for individuals who use wheelchairs is a form of ableism because it assumes that everyone can walk with their two legs and that that is the normative way of experiencing the world. Another example, is not providing closed captioning for a video or film. This is a form of ableism towards individuals who are deaf. The lack of such resources suggests that the normative and “better” way of experiencing said form of media is in an auditory manner. Ableism discounts the experiences of individuals with disabilities and forces them to conform to the normative way of living. There is a great lack of accessibility for individuals who are disabled.





## What is the End Goal of Prenatal Screenings/Diagnostics and Selective Abortions?

Understanding the future of prenatal screenings/diagnostics requires a reproductive justice framework along with a disability rights framework. Throughout this magazine, we've analyzed what it means for someone to be disabled from a sociological and philosophical point of view; we have also examined what role abortions play in our society as a means of reproductive control. This question requires informed thought from multiple framework because the end goal/future direction of prenatal screenings is informed from these various ways of understanding. We will first examine the end goal for prenatal screening from a reproductive justice framework. Reproductive justice is a framework, coined by Loretta Ross, this framework seeks to understand the role abortions play in giving people with uteruses reproductive autonomy. Prenatal screenings were created out of a necessity to inform pregnant people about birth defects, gender, genetic disorders, and other concerns regarding their pregnancy. "Benefits of first-trimester screening include the early gestational age at which results are provided, allowing patients and providers time to interpret results and make decisions surrounding further pregnancy care, including pursuit of further diagnostic testing" (Carlson et. Al 2017). These benefits of prenatal screenings are undeniable and cannot be stripped away from people because it does not allow people to make informed decision to carry out a pregnancy. This can also cause further complications for the pregnant person because prenatal screenings provide information they need to understand if they can carry

out a healthy pregnancy.

Many people rely on prenatal screenings to understand if their body is even capable of carrying out a pregnancy to term without any harm to their bodies. Furthermore, prenatal screenings offer more information regarding conditions that a fetus might have that parents need to prepare for. For example, early prenatal screenings offered information on pregnancies with an increased risk. People over the age of 30 who were not sure if the pregnancy was high risk, would need to prepare for such a pregnancy ahead of time such as having the right vitamins and prenatal care. However, without prenatal screenings, this kind of preparation would be difficult to execute. From a reproductive justice framework, prenatal screenings offer people more information about the process they'll endure during the pregnancy period. From this point of view, it is justified that prenatal screenings aim to provide pregnant people with as much information as possible regarding their pregnancy. Informed consent is an important foundation for which reproductive justice is founded on. If people do not have all the information, they need to make informed decisions, then reproductive justice as a framework fails those it was intended to serve. "Some feminist commentators have argued that the availability of reproductive



choices, including prenatal testing, enhances the autonomy of women by allowing them to have access to information” (Pergament 2013). However, this framework becomes further complicated when the layer of disability politics is added. When prenatal screenings go beyond informing pregnant people the risk of their pregnancy, and selective abortions are available at high rates, this reproductive justice framework becomes more complicated as we try to understand the trajectory of prenatal screenings.

As prenatal screening technology progresses, the conditions that can be tested for expands with it. A study on the ethical implications of prenatal screenings states, “developments in non-invasive prenatal testing (NIPT) may soon provide couples with the opportunity to test for and diagnose a much broader range of heritable and congenital conditions than has previously been possible” (Stapleton 2016). As the technology progresses, so do the bioethical implications of testing for certain conditions without providing information needed for people to make fully informed decisions. While disability rights activists are not calling for the complete end of prenatal screenings, they do point out a very murky bioethical matter as to why these disabilities have such high rates of termination. What does this mean for disabled people when prenatal diagnostic testing and screening becomes more advanced and more accurate in detecting these conditions? Without any subversion in decreasing the rates of abortion, the disabled community remains an unprotected group as prenatal screening technology advances. As time continues, are the high termination rates of fetuses with disabilities supposed to remain unintended consequences of prenatal technology improving? What then becomes the end goal of prenatal screening as it fulfills its goal of informing pregnant people of the conditions of their pregnancy terms but it also contributes to a eugenics practice of selective abortion? Pergament argues in her article, “another unresolved dilemma concerns balancing the responsibilities and choices of [pregnant people] and their partners with the rights of their

potential offspring to have an open future and whether these individual choices should incur liability” (Pergament 2013). It seems that the future of prenatal screenings as it relates to disability rights has no concrete and clear answer as to the trajectory of the tests. Seeing as prenatal screenings lie at an intersection of seemingly conflicting frameworks, it's hard to establish a tangible picture of what prenatal screenings in a justified lens looks like. The dominant framework as we understand it, is the reproductive justice framework and if we only analyze the bioethical implications of prenatal screenings from a reproductive justice framework, then the trajectory of prenatal screenings is clear, more advanced screening technology will lead to more informed patients who will maintain personal autonomy as they decide what is best for their bodies. However, from a disability rights framework, a deconstruction of ableism on a systematic level is necessary to prevent the high rates of selective abortions of fetuses with ‘undesirable’ conditions. These frameworks help us understand that the end goal of prenatal screenings/diagnostics is a hard one to pin down as it complicates how we understand the end goal of reproducing in the first place.





# Word Search

E P S G N M D O F O M M P E C  
 O M Y S Y M A O E L O E R R M  
 U M B M E N K K T R T D E A F  
 P V R R G N E L U O H I G C S  
 V A S F Y U F C S U E C N H H  
 H T R I B O T A O P R I A T C  
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ABLEISM  
 ABORTION  
 BIOLOGY  
 BIRTH  
 DEAFNESS  
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 DISABILITY  
 DOWNS SYNDROME  
 EMBRYO  
 EUGENICS

FETUS  
 FULL TERM  
 GYNECOLOGIST  
 HEALTHCARE  
 MEDICINE  
 MOTHERHOOD  
 PREGNANCY  
 PRENATAL  
 SCREENINGS  
 TAYSACHS

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