Banning Abortions of Down Syndrome Fetuses is Harmful to Disabled People

Over 40 years have passed since the Supreme Court case *Roe v. Wade* affirmed that women have a constitutional right to a safe and legal abortion. Despite this ruling, the debate over the morality and legality of abortion has not ceased in the United States. Traditionally, the debate has been centered upon whether or not a woman’s right to autonomy over her own body and medical decision-making take precedence over the harm done to the unborn fetus, which those who oppose termination may consider to be the moral equivalent of a human life. In recent years, as the prevalence of disability awareness has risen in tandem with the fight for an expansion in civil rights and social welfare for disabled individuals, a new argument has been posited against abortion in cases in which the mother elects to terminate the pregnancy for the sole reason that the fetus is discovered to have Down syndrome (also referred to as intellectual disability). Support for the belief that it is inherently wrong for a mother to seek an abortion discriminately for intellectually disabled fetuses has manifested itself in the form of new laws put forth by conservative lawmakers in numerous states throughout the country. Though these newly proposed laws are being promoted as protective of the disability community, and thus have gained support from some of its members, it is likely that the intention behind them is to prevent or discourage abortion outright in a broader context, and furthermore, that such laws would be an ineffective way of improving the wellbeing of individuals with intellectual disability or their families.

The termination of a fetus due to knowledge that it has a disability is a contentious issue that, until recently, was not prevalent enough to draw attention from lawmakers. Though prenatal testing in various forms has existed since the 1950s, it has historically been invasive (in a matter
that is potentially dangerous to the mother and the fetus), inaccurate, and not easily accessible (Giric 740). As technology has continued to progress and testing has become dramatically more effective and convenient, prenatal screening has become increasingly common (Bradford 2015). Physicians now recommend screening at higher rates and parents, attempting to make every decision possible to ensure a positive outcome for their expanding family, often take the opportunity to gain insight into any potential complications (Giric 738). As such, more and more mothers are faced with a situation in which, knowing that their child has a medical condition such as Down syndrome, they must make a decision as to whether or not they want to carry the pregnancy to term.

A systematic review of 24 separate studies examining trends from 1995-2011 showed that among the data available, there was an average 67% termination rate in cases where prenatal testing showed definitively that the fetus had Down syndrome. Considering the proportion of mothers obtaining prenatal testing, this trend was determined to result in a 30% reduction in the population of individuals with Down Syndrome in the United States (Natoli et al. 145). The data also showed that the rate of termination appeared to be falling over time. Regardless, the termination rate is alarming to many disability advocates who argue that it reflects violent discrimination against individuals with disabilities. It is upon this basis that the state governments of Ohio, Pennsylvania, Indiana, Louisiana, and North Dakota have all considered bills that would outlaw abortion specifically targeting fetuses with Down syndrome (Cha).

The issue at hand is complex and first warrants an explanation as to why abortion, which is legal and at the discretion of the individual carrying the fetus, becomes a more complicated moral issue when the decision to terminate is based exclusively on the disability present in the fetus. Disability advocates argue that it is not a disability itself that impedes a person’s ability to
flourish, but rather the prevalence of discrimination by members of the able-bodied population. The discrimination perpetrated by the “normate” majority comes in various forms including stigmatization of disability, a lack of provisions for financial assistance or work accommodation, construction of inaccessible public facilities, and outright violence (Giric 738). Through this lens, people with disabilities face targeted systemic and interpersonal bias in the same manner that other protected groups often do. Viewing the issue in this manner, if taken to its extreme, then changes the meaning of termination of an intellectually disabled fetus drastically. One disabilities advocate writing for the Charlotte Lozier Institute (an anti-abortion think tank) maintains:

Making such a radical decision as to end the life of a child based upon a first impression is a most horrible and violent form of discrimination. It has no place in an American society that is committed to ending discrimination in any form and that has intensified that effort for persons with disabilities over the last 25 years since the signing of the Americans with Disabilities Act in July 1990. (Bradford)

Whether or not views like these are motivated principally by concern for disability rights (or instead as a means to preventing abortions), lawmakers attempting to advance protections for fetuses with Down syndrome express that they are doing so to combat what they view to be an illegal form of discrimination (Cha).

With so many possible variables to consider in reaching a decision as to whether or not the act of terminating a fetus exclusively due to its status as intellectually disabled should be labelled unlawful discrimination, it is important to consider the intentionality behind the actions taken by parents who decide to terminate. Unfortunately, certain parts of the disability community as well as pro-life advocates have drawn a hasty and false conclusion as to why a
potential parent may choose to seek an abortion upon receiving the news that their future child would have Down syndrome. The assumption immediately placed upon these parents is that they are ableist and maintain a certain bias against individuals with disabilities, and as a result, reject the child with Down syndrome because they do not want that specific child, likely because they could not value it to the same degree as a normate child. These parents are believed to be acting purposefully to avoid association with disability and the accompanying potential for stigma and other challenges that arise from it (Kim).

Although this is a legitimate concern and it may be true in some cases, a deeper analysis reveals that the process by which parents ultimately make their decision is much more complex. A 2009 study that set out to discover the impact of the Americans with Disabilities Act of 1990 on the occurrence of Down syndrome related pregnancy terminations found that, “A complex array of legal, material, economic, technological, social, familial, and medical factors might reasonably inform prenatal testing and selective abortion for Down syndrome (Fox 885).” The study goes on to describe a number of these factors in more depth, finding that parental considerations focused heavily on public funding for various support systems, challenges in attaining transportation to specialized medical facilities, availability of government funding, access to insurance, ability to dedicate appropriate time and resources to caring for a child with a genetic disability, and the perceived burden on one’s self and the family unit in caring for a child with special needs, amongst other factors (Fox 885).

Upon consideration of the multitude of factors that may influence a mother’s ultimate decision, it becomes clear that the issue at hand is not merely one that can be reduced to simple discrimination on the basis of who or what the child has the potential to be. Just as when any pregnant mother is making the difficult decision as to whether or not she wants to carry her
pregnancy to term, considerations are taken as to how plausible it may be to care for the child given the circumstances one finds themselves in. Even when raising a normate child, it is not without difficulty to provide an environment in which they can thrive and ensures the wellbeing of the child and caretaker. Given the exceptional amount of time and money it takes to provide a child with Down syndrome with the necessary specialized care, it should be apparent that what a woman ultimately chooses to do with her fetus is a very individualized decision that cannot and should not be simplified to a simple law that entirely strips her of her freedom.

Personal freedom aside, the chief concern for many mothers is the wellbeing of their child and their family as a whole. The myriad additional responsibilities associated with having a child with intellectual disability is not something that everyone can manage. It has been shown that parents of children with Down syndrome have, on average, greater reported levels of stress and issues with adjustment than parents of developmentally normal children (Sanders and Morgan 15). Parents must also consider, especially if under economic constraints, the fact that a child with Down syndrome may likely need to be under their care for the duration of their life. One 2013 study of intellectual disability in the American workforce found that just 23% of individuals with intellectual disability were employed (and many in sheltered work that pays well below minimum wage) and approximately 17% lived independently (Siperstein et al. 162). Accordingly, many parents are concerned about how their child will be cared for after they themselves die. The answer is often assisted living or group homes, however there are further concerns about quality of life given that individuals with intellectual disability are subject to the highest rates of neglect, sexual abuse, and violent crime amongst populations with varying disabilities (Harell 4). Given the great degree of uncertainty as to where on the spectrum of intellectual disability a child with Down syndrome may be and consequently how vulnerable
they are, many parents find that they cannot make the decision to follow through with the pregnancy in good faith (Cokley).

As a response to the argument just posited, some advocates will point to the fact that with proper support, parents can alleviate significant anxiety and maintain optimism for their child’s future (Toscano and Doyle). It is absolutely true that many individuals with Down Syndrome lead fulfilling lives and many parents are overwhelmingly happy with the opportunity to raise a child with Down syndrome. However, the issue again must be considered at an individual level given that support systems for Down syndrome are so variable. One especially important consideration when raising a child with Down syndrome is education. This starts with early intervention programs in which children are exposed to a variety of stimuli as early on in life as possible in the hopes of maximizing the child’s potential for cognitive development (Solomon 183). Following early intervention, education often continues within the public-school system. Each of these two educational processes are provided by the federal government and are designed to cater to those with special needs, but the quality and ease of access varies widely by region. It is not uncommon for families to move between states just to access the best resources available (Solomon 183). Obviously, doing so would require certain financial means which may also be put toward specialized private education that can be adjusted in a manner to more rigorously meet the child’s specific needs.

People with Down syndrome may also require special medical needs ranging from behavioral counseling to specialized medicine to care for the variety of diseases that occur with increased morbidity in those with Down syndrome, including digestive tract malformation (requiring a special diet), heart defects, joint and muscular defects, psychosis, anxiety, depression, and disruptive-behavior disorders (Solomon 173). Such extensive medical
requirements also necessitate that a caretaker have the time to manage them as well the means to afford them. Even if medical care is covered to a certain degree, which it may not be, transportation costs must also be considered (Manninen). It should be abundantly clear at this point that it takes an extremely dedicated parent to raise a child with Down syndrome. Even though support is widely available and in many cases is government funded, the quality of such support cannot be guaranteed unless one is able to essentially buy it. With so much inconsistency present in the current support systems for those with intellectual disability, it cannot be reasonably expected that all mothers would choose to take on such a burden, especially with the knowledge that, if economically disadvantaged, they would likely not be able to provide even close to the amount of resources necessary to raise a child with an optimum outcome.

Another important component to the argument that targeted abortions of fetuses with Down syndrome should be outlawed is the view held by many disability advocates that such a practice parallels eugenics. The foremost concern is that through selective abortions, the population of those with Down syndrome will shrink or eventually even disappear, reducing the overall diversity of our society. It is argued that this may further stigmatize individuals with intellectual disability and also pass on negative attitudes toward parents who may have chosen to have a child with Down syndrome even with the knowledge that they would be bringing a mentally disabled person into a world where it is difficult for them to fit in (Paul). First, it should be noted that, as stated earlier, the proportion of mothers who choose to terminate their pregnancy after a definitive diagnosis of Down syndrome appears to be trending downward (Natoli et al. 145). Secondly, consideration should be given to the fact that unlike true eugenics, there is no body of power that is any way influencing what women choose to do with their pregnancies. It is illegal for a physician, fertility counselor, or other healthcare professional to
show preference with the intention of manipulating a woman’s choice (Paul). Lastly, as already discussed, the factors contributing to a woman’s decision as to whether or not to have the child are largely grounded in circumstance rather than a valued judgement about the worth of the child itself. Though many advocate that there should be more social support for women who have children with Down syndrome and other disabilities, women are typically seen in a positive light for willingly choosing to raise a child with a disability, contrary to concerns (Toscano and Doyle).

Still, it remains difficult to address how, on a societal level, people with Down syndrome (and disability in general) can be completely destigmatized and given the appropriate support to thrive in the United States. One thing that I believe to be clear is that any bill put forward to outlaw the abortion of fetuses with Down syndrome is misguided. Not only are the true intentions of those backing these bills highly questionable given the conservative proclivity to reduce the occurrence of abortion by any means possible, but the benefit provided to individuals with Down syndrome and their families seems to be negligible. Forcing people to have children with Down syndrome is unlikely to reduce the stigma surrounding people with Down syndrome. It is unlikely that this would bring any additional benefits to the existing population either since the aforementioned 30% reduction in the Down syndrome population by selective abortion would likely not be enough to radically change government funding or the way that the general public views and interacts with people with the disability. Forcing mothers by law to have unwanted children could, if anything, make matters worse. As one Pennsylvania professor and father of a child with Down syndrome wrote on the proposed bills, “If someone is disability-phobic, what is the point of forcing them to have a child that they will resent and potentially mistreat (Berube 4).”
Unfortunately, it does not appear that ameliorating the problems encountered by people with Down syndrome and their families will be as simple as passing a singular bill. Instead, it may be more practical, and even necessary, to attain what disability advocates have long sought and conservatives often vote against: better funding for various forms of social welfare, including early intervention programs, special education, and Medicaid. Currently, the reality that many families face is that they are unable to adequately care for their child with special needs, which may cost upwards of an extra $134 per month (Manninen). In the book *Expensive Children in Poor Families: The Intersection of Childhood Disabilities and Welfare* written in 2000, it was said of low-income families that:

> unless they received federal aid in the form of Supplemental Security Income (SSI) families with disabled children were more likely than other families to be poor or extremely poor, and direct out-of-pocket expenditures pushed between 4 and 12 percent of families with disabled children into extreme poverty. Families with disabled children were also more likely than others to report hunger, housing instability, unpaid bills, and utility shutoffs. (Meyers et al.)

Poverty presents possibly the greatest barrier to managing a disability, and it is likely that income may play a large role in whether or not parents choose, knowing their child will have Down syndrome, to carry their pregnancy to term.

Socioeconomic status is one of the most deterministic factors as to whether or not a mother will have an abortion (Manninen). In many cases, it is not the mother’s desire to have a baby that ultimately makes her choice. Instead, it is often the realization that it would be impossible to maintain a stable life with the addition of a newborn that requires such extensive care. Philosopher Rosalind Hursthouse said when discussing abortion there is something
“terribly amiss in the conditions of [our] lives, which makes it so hard to recognize pregnancy and childbearing (and in this case, caring for a child with Down syndrome) as the good that they can be (Hursthouse 240).” She concluded that it is often pressure imposed upon individuals from the society which they belong to that drives their decisions. Instead of acting freely, as many women might in choosing to keep a baby with Down syndrome, they cannot escape the thought of failing to provide to this child, who has unique needs, what he or she needs to be a productive and viable member of the society constructed for normates. With the expansion of social welfare and a purposeful effort by various institutions throughout our society to be as accommodating as possible for those who, by no choice of their own, live with disability, it is possible that productive change could follow for people with Down syndrome and that the fear women feel bringing an intellectually disabled child into the world could be mitigated.
Works Cited


