

Down Syndrome: Blurring the Line Between Disability Rights, Women's Rights and Eugenics

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Abstract: Although the battle over reproductive rights began early in the United States' history, it is still highly controversial. The fight over abortion becomes more complex when considering abortions of fetuses that have been diagnosed with genetic anomalies, with one of the most common examples being Down syndrome. Some who receive a prenatal Down syndrome diagnosis may be unsure of whether to continue the pregnancy. They often consider numerous factors, including medical and financial implications, emotional toll on all family members, quality of life of those with Down syndrome, and, perhaps most importantly, whether an abortion of a fetus diagnosed with Down syndrome is legal. These decisions are highly dependent on the individual circumstances of each potential parent and their family. On a societal level, however, Down syndrome abortions contribute to a larger conversation about the conflict between disability rights and reproductive justice. This case follows the journey of Maggie Reardon, a pregnant woman faced with a prenatal Down syndrome diagnosis. It investigates the unique pressures women experience when deciding whether to abort a fetus diagnosed with Down syndrome and how such constraints may impact their choices. It also explores the complex perspectives of the disability rights and reproductive justice movements.

Girl or Boy?

The choice Maggie Reardon faced would leave many women conflicted, but she made the decision easily. Maggie had been offered a simple, noninvasive blood test that would allow her to find out the sex of her baby (Reardon 2015). It would pose zero risk to the fetus and would allow her to learn the sex twelve weeks into her pregnancy, which was eight whole weeks earlier than she would find out if she waited to learn via ultrasound (Reardon 2015). Maggie was so excited to have her first child; for her, choosing to accept the test was easy.

She waited impatiently for the phone call from the genetic counselor, eager to use the incoming information to realize her dreams of starting a family with her husband. Then the phone call came, and suddenly, Maggie's excitement transformed into devastation. Her fetus had been diagnosed with Down syndrome. Her first thought: everything she had imagined for her child, for her family, had been lost (Reardon 2015). Maggie "felt like [she] had been sucker punched" (Reardon 2015, n.p.).

The Test

While there are many people who, like Maggie, choose to accept the blood test, many others refuse it. Their hesitation does not necessarily lie with learning the sex of their baby, but

rather because it can reveal much more than the baby's sex. The simple test, MaterniT21, arose as a method to analyze the mother's blood for fragments of the fetus's DNA and look for the presence of extra chromosomes when the mother is only 10 weeks into her pregnancy (Hill 2012). These results then indicate, with almost 100% accuracy, whether the fetus has Down syndrome (DS), a genetic condition caused by an extra full or partial copy of chromosome 21 (Hill 2012; National Down Syndrome Society [NDSS] n.d.-b).

People with DS often have unique physical features, such as low muscle tone and small stature, cognitive delays, and an increased risk for medical conditions like heart defects and Alzheimer's disease (NDSS n.d.-a). Some people celebrate MaterniT21 for its early diagnosing capabilities, but others worry about its ethical ramifications—for example, how pregnant people should proceed if they are given an unexpected diagnosis (Hill 2012).

Being 39 years old at the time of her pregnancy, Maggie was of advanced maternal age; her fertility was declining, and she was at a greater risk for complications like miscarriages or birth defects (Reardon 2015; The American College of Obstetricians and Gynecologists n.d.). She and her husband had consequently assumed that her fertility would be their major roadblock to becoming parents. To their surprise, Maggie became pregnant relatively easily, and her thoughts about what her future child would be like were filled with happiness and wonder: "Is she going to look like me, ... read Judy Blume like I did, ... have a sense of humor?" (CBS News 2015, n.p.). Her age gave her a one percent chance of having a baby with DS, but this risk never concerned her.

Even if the risk had been worrisome for Maggie, when she accepted the offer for the blood test, she firmly believed, and even said out loud, that she would not have an abortion regardless of whether the fetus had any genetic abnormalities (Reardon 2015). Women choose not to get the test for a variety of reasons, but Maggie said yes simply because she wanted to learn the sex of her baby as soon as possible. That decision had consequences, however, and now, having received the news that the fetus was diagnosed with DS, Maggie's initial resolve to keep the pregnancy in all circumstances began fading quickly. She sobbed on her couch, her "daydreams shattered," and mourned for "the loss of the child [she] thought [she] was supposed to have" (CBS News 2015; Reardon 2015, n.p.).

Legality of Abortion in the U.S.

At the time the United States was founded, abortions were relatively common procedures (Gale 2018). They could be performed until quickening, or the first time the pregnant person feels the fetus move, which typically happens around the fourth or fifth month of pregnancy (Baker 2020). That being said, the federal government allowed the states to control the legal status of abortions, and in 1821, Connecticut became the first state to pass a law prohibiting abortions (Gale 2018). By the end of the 19th century, 49 states and the District of Columbia had all declared abortions to be illegal unless if they were necessary for the life or health of the mother (Baker 2020; Gale 2018).

With the use of chemical abortifacients increasing,¹ the very first abortion regulations were intended as poison control measures, but other factors motivated the development of increased restrictions (Baker 2020). The wide denial of access to abortions was a response to the developing women's rights movement; it reaffirmed a patriarchal society by quashing the growing idea of "voluntary motherhood" and reinforcing women's societal position as mothers (Baker 2020, n.p.).

¹ Chemical abortifacients are chemicals that induce abortions.

Such restrictions allowed male doctors to gain control over the highly profitable birthing industry, which, at the time, was dominated by midwives, many of whom were women of color (Baker 2020). These laws also aimed to ensure that white Protestant women would have more children, countering the declining birthrate among U.S.-born white Protestant women and the recent influx of Catholic immigrants entering the United States (Baker 2020).

Abortion laws could not stop abortions completely, but they did decrease access to safe procedures, particularly for women of color, leading some states to eventually liberalize their abortion laws (Baker 2020; Gale 2018). In the 1960s, some women began speaking out against abortion bans to illuminate the danger behind such illegal procedures (Baker 2020). In response to the growing calls to make abortion safe and legal, in 1967, Colorado passed a law that allowed women to have voluntary abortions (Baker 2020; Gale 2018). It was the first of the states to do so, and four states followed Colorado's lead and repealed their anti-abortion laws, with 14 others opting to loosen theirs (Gale 2018). For example, New York allowed abortions in cases of rape or incest, and Hawaii legalized abortions through 20 weeks of pregnancy, but only for residents of the state (Baker 2020).

Then, in 1973, complete state control over the legality of abortions, which had lasted for over one hundred years, changed with the ruling of *Roe v. Wade*—the Supreme Court declared total abortion bans to be unconstitutional nationwide (Gale 2018). According to the ruling, unborn fetuses were not to be legally considered as people, and women had the right to determine whether they wanted to have an abortion in the first trimester of pregnancy (Gale 2018). States could decide the legality of abortions performed in the second trimester and those done after the fetus reaches viability, the time when the fetus can survive outside of the womb (Gale 2018). The point of viability was and continues to be unclear, generating questions as to when states can legally restrict abortions (Gale 2018). Similarly, states could not regulate abortions in cases where having the baby could endanger the health of the mother, but states define these conditions differently (Gale 2018).

The Supreme Court decided another case, *Doe v. Bolton*, on the same day as *Roe v. Wade*. The ruling declared that laws that required hospital admission, approval from a hospital abortion committee, a second and third medical opinion, and legal residence in a state for abortions to be performed were illegal; they were deemed excessive and restricted pregnant people's rights to have an abortion (Abboud 2017; Gale 2018). The Court also declared the emotional and psychological health of the mother as important factors to consider when determining if a pregnancy would harm the mother's health (Gale 2018).

These rulings were celebrated by pro-choice activists around the country, but the opposing anti-choice movement was also gaining momentum at the time, with the National Right to Life Committee forming in 1968 and the Americans United for Life organization developing in 1971. These organizations, along with other anti-choice activists, contested the court rulings. They argued that the legal status of unborn fetuses is inconsistent: fetuses are not legally considered persons, but they have the right to inherit property, and those found guilty of wrongfully killing an unborn fetus can be charged with manslaughter (Gale 2018).

Following *Roe v. Wade*, over one thousand legislative proposals regarding abortion were introduced in Congress, with a large majority aiming to restrict abortion availability. These proposals led the Supreme Court to consider a wide variety of potential abortion regulations,

including informed consent,² mandatory waiting periods, spousal and parental consent, and parental notice (Shimabukuro 2022). Several cases led to further regulations of women's reproductive rights. For example, the rulings of *Maher v. Roe* in 1977, *Harris v. McRae* in 1980, and *Rust v. Sullivan* in 1991 gave state governments the choice of whether to use federal funding for abortions (Shimabukuro 2022). Because many states opted not to use federal funding for abortions, these cases, along with other federal and state initiatives, created significant abortion barriers for pregnant people of lower socioeconomic classes, such as citizens with Medicaid (American Civil Liberties Union n.d.). *Webster v. Reproductive Health Services* ruled in favor of Missouri's restriction against using public employees and facilities for abortion procedures (Shimabukuro 2022). Although the decision did not affect private doctors' offices or clinics, it still restricted abortion access, especially for patients of lower socioeconomic status who relied on these employees and facilities (Shimabukuro 2022).

The Supreme Court made a landmark decision affecting abortion laws in the 1992 case *Planned Parenthood of Southeastern Pennsylvania v. Casey* (Planned Parenthood of Southeastern Pennsylvania v. Casey n.d., n.p.). The court maintained pregnant people's right to an abortion by concluding that state abortion laws could not impose an "undue burden," or a "substantial obstacle in the path of a woman seeking an abortion before the fetus attains viability" (Planned Parenthood of Southeastern Pennsylvania v. Casey n.d., n.p.). The undue burden clause was later used to strike down several state abortion regulation laws. For example, *Whole Woman's Health v. Hellerstedt* investigated a Texas law that required physicians performing abortions to have admitting privileges at a hospital within 30 miles of the site of abortion; it also required abortion sites to meet the standards of ambulatory surgical centers, which would be costly and unnecessary (Shimabukuro 2022). The Court determined that this law placed an undue burden on a woman's ability to have an abortion and was therefore unconstitutional (Shimabukuro 2022).

None of these court cases resulted in a direct prohibition of DS abortions, but they exemplify the legal protections and obstacles that women may encounter when seeking an abortion. The cases also represent repeated efforts by state governments and anti-choice agencies to restrict abortion access. In fact, if Maggie lived in certain states or became pregnant just a couple months later, her decision regarding her pregnancy may have been made for her.

On March 26, 2013, North Dakota became one of the few states to join the discourse of disability versus reproductive rights (Eligon and Eckholm 2013). The state passed a series of three abortion laws set to go into action in August of that same year (Eligon and Eckholm 2013). The first law banned abortions once a fetal heartbeat could be detected, which can occur as soon as six weeks of pregnancy (Eligon and Eckholm 2013). The second aimed to shut down the state's only abortion provider by requiring physicians performing abortions to have admitting privileges to a local hospital (Eligon and Eckholm 2013). The third law banned performing abortions based on the baby's sex or genetic defects, including DS (Eligon and Eckholm 2013). While the first law was eventually declared unconstitutional by the Supreme Court in 2016, the second and third are still in effect today (Chappell 2016; Guttmacher Institute 2016b). Similar laws preventing abortions on the basis of fetal genetic anomalies currently exist in Mississippi, Missouri, Ohio, South Dakota, and Tennessee, but other states have tried or are trying to restrict these abortions as well (Guttmacher Institute 2016a). Like North Dakota, these states frame such laws as a protection

² In the context of reproductive health services—for example, abortions—informed consent is defined as complete and comprehensible information on the procedure and possible alternatives. If the patient desires, counseling can also be provided. Informed consent is done to ensure that the patient can make a well-informed decision, but anti-abortion activists often take advantage of patients by requiring that patients be given outdated, biased, or even incorrect information (Richardson and Nash 2015).

of disability rights, but, to many, these laws simply serve as another limitation of women's reproductive rights (Guttmacher Institute 2016a; Hoban 2021). Living in New York, Maggie would not have to worry about legal issues should she choose to have an abortion, but that did not ease her uncertainty about her pregnancy.

The Price of Down Syndrome

Even though legal issues were not a concern for Maggie, the many other potential challenges she could face should she choose to keep the pregnancy complicated her decision; with the rate of DS abortions in the United States being estimated at 75%, she would not be alone no matter what she chose to do (Reardon 2015). The costs associated with DS are one of the many factors that potential parents like Maggie may consider after learning of a prenatal DS diagnosis. One 2016 study found that, in the United States, parents of children with DS, on average, spend \$84 more per month on medical expenses than they would if caring for a typically developing (TD) child, with the expenses generally decreasing as the child ages (Kageleiry et al. 2017). From birth to age 18, these parents spend a total average of \$18,248 more on medical expenses than they would caring for a TD child (Kageleiry et al. 2017). The expenses, particularly those in the first few years of life, can also increase drastically if the child is born with a congenital heart defect or other major birth defect; as children with DS are more at risk for having such conditions, these potential financial burdens are a relevant consideration to expectant parents (CDC 2018).

While the extra economic burden of caring for a child with DS may be manageable for some, the 2016 study only investigates the out-of-pocket costs for families with insurance; lack of insurance could be devastating to a family's financial situation if they have a child with DS. On average, all medical costs over the first 18 years of life, including those paid by health insurance, are \$230,043 more for children with DS than for TD children (Kageleiry et al. 2017). This difference would make a substantial impact on the finances of most families, but those with health insurance may be able to avoid the worst of these expenses. As a result, raising a child with DS may be much more financially difficult for families without medical insurance or a lower household income, leading to disparate impacts based on income and insurance status.

Expanding the lens of the calculation to estimate the lifetime cost of DS on a family is a complicated task. Some estimates suggest that lifetime costs of DS may range anywhere from \$680,000 to \$900,000; these prices include both direct costs, like medical expenses and long-term care, as well as indirect costs such as lost wages due to DS morbidity and mortality (Kageleiry et al. 2017). For many families, these financial implications may be impossible to afford, especially when considering that parents already face an average cost of \$233,610 to raise a typically developing child from birth to age 18 (Lino 2020). These high costs associated with DS may be one of the many reasons why pregnant people consider having a DS abortion, especially if families lack the income or outside financial support to afford them.

Some assistance for families with children with DS does exist. For example, federally supported early intervention programs provide therapy for children with disabilities ages three and younger with the aim of addressing some of the developmental delays they experience (NDSS n.d.-c). Many families can enroll their children with DS in early intervention programs at little or no cost, though the exact price of these programs varies from state to state (NDSS n.d.-c). Afterwards, local school districts are federally mandated to grant these children access to free, appropriate, public education (NDSS n.d.-c).

Such government support can be helpful, but it may not be enough to allow a family to afford having a child with DS; part of the financial discrepancy between raising children with DS

versus TD children comes from the potential income that is lost due to the morbidity and mortality associated with DS. Like Maggie, many potential parents hope their children will become successful, independent adults, but these aspirations can be limited by a DS diagnosis. Unemployment rates continue to be high among individuals with DS (Lee, A. Knafl, K. Knafl, and Van Riper 2021). There are few employment options available to people with DS, and many of these options are low-paying or have poor working conditions (Lee, A. Knafl, K. Knafl, and Van Riper 2021). Thus, families with children with DS may have the additional financial burden of supporting their children with DS who, as adults, are unable to obtain employment or live on their own.

Still, the possibility of having to find long-term care for a child with DS may be even more daunting than unemployment or a low-paying job. Unlike medical care, special needs care is usually not covered by private insurance (Care.com 2022). Personal care assistants cost an average of \$19 an hour, adult day programs are an average of \$15,520 a year, and getting a private room in a licensed nursing home is, on average, \$77,745 a year (Care.com 2022). Financial assistance in covering these expenses may be received through Medicaid or other disability benefits like Supplemental Security Income or Social Security Disability Insurance, but some people may not qualify (Care.com 2022). Such expenses may be one reason why, in many studies investigating families with children with DS, most of these families have incomes that place them within the middle or upper socioeconomic classes (Lee, A. Knafl, K. Knafl, and Van Riper 2021; Piepmeier 2013; Skotko, Levine, and Goldstein 2011c).

Fortunately, financial issues were not a concern for Maggie and her husband. They were both well-educated and had established careers and supportive families. Accessing the resources, knowledge, and social support needed to adequately provide for a child with DS would not be a concern for them (Reardon 2015). That was enough for Maggie's husband, who, despite his fears of raising a child with DS, believed they should continue with the pregnancy. Her husband affirmed, however, that the decision was hers to make (Reardon 2015).

Neither the lack of financial concerns nor her husband's support made the decision any less difficult. Maggie might not have to worry about finances or emotional support, but those are not the only complications associated with DS. She also continued to struggle with the idea of having a life and family that completely differed from the one she had dreamt of for so long (CBS News 2015; Reardon 2015). Facing the reality of possibly having to care for a child with DS for their entire life, Maggie was left wondering, "Am I going to be able to love this child?" (CBS News 2015, n.p.). For her, the answer meant the difference between keeping the pregnancy or having an abortion, and, with it, the chance to start again and have a life without the financial, medical, and emotional risks associated with DS (Reardon 2015).

Maggie's Investigation: Down Syndrome and Health

Faced with a daunting decision, Maggie was determined to learn more about the genetic condition—the information could determine whether she would choose to keep the pregnancy (Reardon 2015). She started by looking at the medical aspects of DS, and like many parents, did not find the information much more comforting than the original diagnosis. Common facial features of people with DS include a flattened face, small head, short neck, protruding tongue, upward slanting eye lids, and unusually shaped or small ears (Mayo Clinic Staff n.d.). Although superficial, these features can still be harmful to people with DS, as they allow for others to easily distinguish those with DS; such separation could lead to social isolation or discrimination. People with DS also tend to have poor muscle tone, increased flexibility, and a shorter stature (Mayo

Clinic Staff n.d.). However, perhaps the greatest physical health fears parents face are the medical risks associated with DS: about half of the babies born with DS have congenital heart defects, which can be fatal in some cases (Boston Children's Hospital n.d.). Due to modern advancements in medicine, most of these defects are treatable—for example, through medications or, in many cases, surgery—but children can still have shorter life spans or long-term health consequences (Global Down Syndrome Foundation 2019). For instance, many of those with heart defects who do survive can also develop pulmonary hypertension, which can cause permanent lung damage if it is not treated (Boston Children's Hospital n.d.). Children with DS may also have other health issues that can affect their quality of life and independence, such as hearing loss, vision, ear infections, or sleep apnea.

Down syndrome also affects people's cognitive abilities. All people with DS have an intellectual disability, with most having a mild or moderate intellectual disability (Boston Children's Hospital n.d.; Rutter 2019). People with mild intellectual disabilities can typically learn how to do everyday tasks like reading, holding a job, or taking public transportation independently, though this learning process can be difficult; those with moderate intellectual disabilities usually require more support (Boston Children's Hospital n.d.). Children with DS also tend to reach developmental milestones later than TD children and struggle with their attention spans, verbal memory, and expressive communication (Boston Children's Hospital n.d.). Behavioral problems like stubbornness, impulsivity, and temper tantrums are also common (Boston Children's Hospital n.d.). All that being said, many children with DS still have strong social skills and visual learning capabilities, and many can participate in regular classrooms, potentially with accommodations (Boston Children's Hospital n.d.). Early developmental and special education services can also help children with DS lead fulfilling lives by addressing some of the everyday challenges caused by DS (Boston Children's Hospital n.d.).

Children with DS are obviously the most affected by these symptoms, but the medical implications of DS can take a serious emotional toll on their parents as well. Although it may seem like a given to some, researchers note that parents of children with DS love and feel proud of their children (Coffey 2021). Still, parents do experience some emotional turmoil because of the medical challenges associated with DS (Coffey 2021). They recall hearing hurtful comments from medical professionals, who seem to only focus on their children's DS diagnoses, discussing their children's pain or developmental delays rather than celebrating their accomplishments (Coffey 2021). That is not to say that parents do not see their children's suffering—parents note that it can be devastating to see their children suffer physically or fail to reach typical developmental milestones (Relf 2014). Parents also experience distress when observing their children become extremely frustrated if they cannot adequately communicate their feelings (Coffey 2021). Having to constantly care for children with DS can be both stressful and emotionally exhausting for parents, especially if their children are less physically independent (Relf 2014). In addition, parents may feel guilty for possibly enabling their children's suffering, and those who are faced with the dilemma of whether to have a DS abortion realize they will feel pain no matter what decision they choose (Relf 2014; Treussard 2014).

Maggie found none of this information easy to swallow, but her lack of connections with people with DS made all her findings even more intimidating (Reardon 2015). Maggie discovered some reasons for hope—for instance, while the list of potential health issues associated with DS seems overwhelming, many can be easily managed, and the life expectancy for people with DS has increased from age 10 in 1910 to over 60 today (Reardon 2015). She understood that this knowledge alone was not enough to give her a complete picture of DS, so she continued to scour

the Internet, needing to know what daily life was actually like for people with DS (Reardon 2015). What she found was a relief: “In short, someone born with Down syndrome today has the same chances the rest of us have of living a fulfilling and productive life surrounded by people who love them” (Reardon 2015, n.p.). Perhaps she could keep the pregnancy and still raise a happy family, just as she had been dreaming about all along.

Looking Beyond Medicine: Quality of Life and Future Prospects

Several studies support Maggie’s findings and suggest that, despite the numerous challenges that people with DS face during their lifetimes, many of them have a high quality of life. In general, people with disabilities perceive their quality of life to be better than how nondisabled people believe it to be (Kaposy 2018). One survey of people with DS ages 12 and older found that 99% of respondents are happy with their lives, 97% like who they are, and 96% like how they look (Skotko, Levine, and Goldstein 2011c). People with DS are also shown to have positive social relationships, with almost 99% of respondents expressing love for their families, 97% liking their siblings, and 86% believing that they could easily make friends (Skotko, Levine, and Goldstein 2011c). Only 4% of respondents were sad about their lives—some respondents said they were both happy and sad about their lives—and 15% felt that their parents paid more attention to their siblings and not enough to them (Skotko, Levine, and Goldstein 2011c). When asked open-ended questions, participants encouraged parents of children with DS to love their children and urged physicians to see the value of people with DS (Skotko, Levine, and Goldstein 2011c). For potential parents considering having a DS abortion, these perspectives could be monumental in what they envision for their potential child and, consequently, how they decide to act.

Though the study provides some insight into the perceived quality of life of people with DS, the results should be carefully considered because the study has several limitations. Parents may have skewed the results, as they were permitted to help their children answer the survey as needed (Skotko, Levine, and Goldstein 2011c). Additionally, the study may support unreliable conclusions if considered alone because the median income of the surveyed families was much greater than the median income of general Americans, thus possibly overlooking the experiences of some children with DS (Skotko, Levine, and Goldstein 2011c). Because the United States does not have a national database of people with DS, the study found participants by sending surveys to all the families belonging to six different non-profit DS organizations across the country (Skotko, Levine, and Goldstein 2011c). This methodology may have allowed for some selection and nonresponse bias that, as a consequence, potentially prevents the study from capturing a complete picture of the quality of life of children with DS in the United States.

A perceived high quality of life among individuals with DS may not surprise some people, especially considering the stereotype that people with DS are more cheerful than TD people (Lee, A. Knafl, K. Knafl, and Van Riper 2021). It should be noted, however, that, like many stereotypes, this one is not necessarily true—people with DS may not actually be more cheerful than TD people. One multinational study conducted a parental survey regarding the quality of life of their children with DS. Overall, the study’s findings aligned with the previously mentioned data—it found that children with DS generally have moderate to favorable physical and financial wellbeing, learning abilities, self-determination, interpersonal relations, social inclusion, and rights (Lee, A. Knafl, K. Knafl, and Van Riper 2021). This study also noticed, however, that children with DS frequently had a lower than moderate emotional wellbeing, especially as they reached adolescence (Lee, A. Knafl, K. Knafl, and Van Riper 2021). Several other studies mirrored this multinational study’s conclusions. For example, one study that found that children with DS had poorer psychosocial

health than their TD peers, and another found that, when presented with one phenotypically TD doll and one doll with phenotypic features of DS, children with DS, particularly younger children, preferred the TD doll and attributed more positive qualities to the TD doll than the DS doll (Lee, A. Knafl, K. Knafl, and Van Riper 2021; Saha et al. 2014). Altogether, these studies indicate that many people with DS have a higher quality of life than expected, but their overall well-being may still remain lower than that of TD children. Whether this trend is due to their medical condition or societal influences like ableism is unknown.³

Ableism has been pervasive throughout United States history, resulting in the relatively strict separation of people with disabilities from the rest of society until recent years. Such separation explains why, like Maggie, many of today's parents grew up having few interactions with peers with disabilities; middle-aged Americans may only be the first or second generation of people to attend schools with students with disabilities (Burns 2020; Reardon 2015). In 1954, *Brown v. Board of Education* gave students with disabilities the legal right to integrated education settings, but most students with disabilities who attended public schools continued to learn in separate classrooms and rarely interacted with their TD peers (Burns 2020). Other children with disabilities lacked the opportunity to attend public schools altogether, as the institutionalization of children with disabilities in medical or care facilities lasted until the early 1970s (Burns 2020). Even after this institutionalization stopped, these children were oftentimes denied from public schools, placed in regular classrooms without the support they needed to succeed, or, similar to what Maggie observed as a child, they “went to a ‘special’ school” or classroom separate from TD students (American Psychological Association 2017; Reardon 2015, n.p.).

Today, children with disabilities may have more opportunities for integration into mainstream society. In 1990, the Individuals with Disabilities Education Act, or IDEA, began ensuring that all children with disabilities had access to a free public education that meets their needs and prepares them for future education, employment, and independent living (American Psychological Association 2017). The act is a significant reason why many children with DS can attend schools or activities with TD children; much to the relief of parents of children with DS, TD children often welcome and celebrate their peers with DS (Coffey 2021). Some individuals with DS may even advance beyond their K-12 education to go on to attend college, get a job, and have significant others during their adulthood (Coffey 2021). These accomplishments may partially explain why several studies have found people with DS to have such a high quality of life.

Such possibilities provide hope to Maggie and other potential parents who receive a prenatal DS diagnosis. There are still numerous risks—even if children with DS have more typical childhoods, they may experience complications during adulthood. Alongside health challenges, they may also experience emotional or psychological difficulties. Studies have found that about 70% of adults with DS tend to be happy, but adults with DS may still struggle with other aspects of their wellbeing; for example, a lack of privacy is a common social concern, and emotionally, some adults with DS are not able to fully comprehend death or dying (Brown, Taylor, and Matthews 2001). Moreover, adults with DS are at a greater risk for developing Alzheimer's disease than TD people, a condition that can severely affect independence and quality of life at an old age (NDSS n.d.-a). Still, parents who initially believed that their children's lives would be severely limited by DS may be relieved to learn that their first impressions may not have been entirely accurate (Reardon 2015).

³ Ableism is defined as the discrimination against people with disabilities and people who are perceived to have disabilities.

The Fateful Party

Unlike Maggie's previous research, learning that her child with DS could have an enjoyable, fulfilling life did somewhat ease her initial despair, but that comfort still was not enough to make a decision (Reardon 2015). The research process had been frustrating as well; she had grown tired of reading parent blogs that described their children as being "angels sent from heaven," being "extra special," or "magically poop[ing] rainbows and pee[ing] daisies" just because they had DS (Reardon 2015, n.p.). She wanted to hear "real stories, both good and bad" (Reardon 2015, n.p.). This desire led her to reach out to Gigi's Playhouse, a nonprofit organization that offers support, therapy, and educational programs to children with DS and their families in the United States and Mexico. Within an hour, Britt Sady, the director of Gigi's Playhouse in New York City, called her back with an invitation to the upcoming party the organization was holding in celebration of World Down Syndrome Day (Reardon 2015). The party would give Maggie the chance to meet with families of children with DS, and, more importantly, allow her to meet children and adults with DS. Still unsure of how to proceed with her pregnancy, Maggie accepted this invitation and, unbeknownst to her, uncovered the final piece of information that she needed to make her decision (Reardon 2015).

No Right Answer

Given all the complexities surrounding the decision of whether to terminate a fetus diagnosed with DS, families are bound to react differently. Approximately 25% of parents in the United States choose to keep the pregnancy, and they are often happy with this decision. Almost all these parents go on to become disability advocates in some shape or form, with some being more public than others (Coffey 2021). They may fight for their children to get the assistance they need to thrive or push for competitive employment for people with DS (Coffey 2021). Others may choose to write memoirs about their journey having a child with DS and how they and their families have changed for the better because of this child—perhaps not financially, but through their relationship with their child and the lessons their child has taught them (Kaposy 2018).

Some studies have reflected these parents' positive experiences on a larger scale. One survey of over 2,000 parents of children with DS from various parts of the United States found that almost all these parents are happy to have their children with DS, love their children, and are proud of them (Skotko, Levine, and Goldstein 2011b). Many state that their children have taught them to be more patient, accepting, kind, flexible, tolerant, and empathetic (Skotko, Levine, and Goldstein 2011b). That being said, about 11% of parents report that having a child with DS strained their marriage, 5% say they are embarrassed by their children with DS, and 4% say they regret having their children (Skotko, Levine, and Goldstein 2011b). It should be noted, however, that parents reporting these negative experiences are more likely to report their children having significant learning disabilities and complex health problems (Skotko, Levine, and Goldstein 2011b).

The statistics in the aforementioned study may be slightly skewed—some parents of children with DS regret having kept their pregnancies, but, unlike the many who write happily about their children with DS, those who struggle rarely speak out. These parents' silence may be due to shame of their feelings or fear of judgment from others. At a local Copenhagen Down syndrome group, one mother claimed that, although she loves her child with DS, she wishes she had had an abortion (Zhang 2020). Her child is frustrated with his inability to communicate, and he lashes out by biting others, including his siblings and parents (Zhang 2020). She struggles to

reconcile the pain he consistently causes her with the love she has for him, pointing out, “If you have a husband that bites you, you can say goodbye ... but if you have a child that hits you, you can’t do anything” (Zhang 2020, n.p.). Another woman, Gillian Relf, shared in a news article that she wishes she was able to have an abortion. At the time of the article, her son with DS, Stephen, was 47 years old but could not care for himself more than a toddler could (Relf 2014). He could only speak a few words and instead communicated with a form of sign language (Relf 2014). While Gillian loves and protects Stephen, she wishes she had had an abortion to avoid “Stephen’s constant suffering” and “the almost daily destruction” his genetic condition has wreaked on the lives of Gillian and her family (Relf 2014, n.p.). She admits that Stephen has sometimes “brought a magical, childlike quality” to the lives of her, her husband, and her TD son, but she does not deny that she would much rather trade that for having him be employed or settled with a wife and kids (Relf 2014, n.p.).

Gillian is not alone in her feelings. Testimonials from mothers have revealed they experience a range of emotions, from love and pride to grief, anger, fear, loneliness, unworthiness, guilt, and pain (Emotional Impact n.d.). The greatest emotional impacts on parents of children with DS are often felt during the initial diagnosis and the period immediately after (Emotional Impact n.d.). After some time, and with support from others, many parents are able to accept the diagnosis and grow to love and be proud of their child, but some still experience negative feelings, such as frustration with slow developmental milestones (Emotional Impact n.d.).

Following the diagnosis period, some mothers of children with DS may continue to struggle. One study discovered that mothers’ stress levels were found to increase significantly as their children advanced through childhood, possibly due to uncertainty about the future or difficulty obtaining services (Bourke et al. 2008). Aging and uncertainty may not be the only stressor, however, as another study found that, in general, mothers of children with DS may experience poorer physical and mental health than mothers of TD children. The degree to which mothers were affected varied depending on their children’s behavioral difficulties, everyday functioning abilities, and current health status (Bourke et al. 2008). This study was conducted in Western Australia, but the factors that the study found to negatively affect maternal mental health still impact many mothers of children with DS regardless of where they live. Gillian, a United Kingdom (UK) resident, is an example of that, as she was admitted into a psychiatric hospital after suffering from a nervous breakdown when Stephen was an infant (Relf 2014).

Gillian’s unhappiness is a reminder of the gravity of the dilemma women and their partners face when deciding whether to keep a pregnancy after receiving a DS diagnosis. She understands the possible consequences firsthand, which is why she pushes people not to judge those who may choose to have a DS abortion. Instead, couples facing this decision should be allowed to do what is best for them (Relf 2014).

This advice is sound—oftentimes, the couples who have an abortion do not regret their decision (Claire 2020; Relf 2014). Still, like those who wish they had had an abortion, the women who speak out about their experiences are few and far between. In addition, while DS abortions may not be rare, no studies have investigated the experiences of those who have had a DS abortion. Thus, they can only be learned about from the few who volunteer to share their own stories. For example, one woman, writing under the pseudonym of Claire, explains how, after two miscarriages, she and her husband discovered they were pregnant. The same day the two of them planned to share the news with her family, they discovered the fetus could have DS. Test results confirmed the possibility one week later, and although she and her husband initially intended to keep the pregnancy, they eventually decided to have an abortion after much deliberation (Claire

2020). The procedure was highly emotional for her, and she continues to think about the fetus that she lost. Still, she is at peace with her decision. Having an abortion was the right decision for her and her husband, and, like Gillian, Claire encourages other couples to do what is right for them (Claire 2020). In some cases, that may mean keeping the pregnancy. In others, it may mean having an abortion.

A Sibling's Perspective

Although Maggie did not have any children when she received the prenatal DS diagnosis, some families do, prompting them to question how having a child with DS could affect their other children; this question is also important for those who do not yet have any children at the time of the diagnosis but hope to have more than one child in the future. These parents may be happy to hear that, according to one study, TD children may benefit from having a family member with DS. The previously discussed survey of parents of children with DS found that most parents believed that their TD children were more caring and sensitive because they have a sibling with DS (Skotko, Levine, and Goldstein 2011b). In addition, one survey of over 800 siblings, ages nine and older, of children with DS found that almost all participants love and are proud of their siblings with DS, with older siblings feeling that their younger siblings with DS make them better people (Skotko, Levine, and Goldstein 2011a). Less than 10% of the siblings reported feeling embarrassed by their sibling with DS, and fewer than 5% would trade their sibling for another sibling without DS (Skotko, Levine, and Goldstein 2011a). Some siblings do feel burdened by extra chores and caregiving responsibilities, but 90% of the older siblings surveyed indicate that they plan to help care for their siblings with DS when they become adults; other studies have suggested that they may view this future caregiving positively rather than as a burden (Skotko, Levine, and Goldstein 2011a). Overall, this study suggests that many children may appreciate having a sibling with DS.

Having a sibling with DS may not always be a positive experience, however. Some parents of children with DS have noted that balancing caring for their children with DS and spending enough time with their TD children can be difficult and sometimes leaves their TD children feeling neglected (Coffey 2021). A study that interviewed 23 adolescent siblings of children with DS highlighted further nuances of having a sibling with DS (Graff et al. 2012). One 18-year-old sister of a child with DS—who has diabetes and has undergone several surgeries—explains the complexity of this experience as follows:

It's so much fun. She can be kind of crazy at times, and it can be kind of hard watching other sisters that are around our same age and see how functional that the little sisters are and how much ... they do with each other. It's kind of hard when I see [child's name] and I know that we're never going to have those kinds of things, but I feel like ... it's great. It's really hard sometimes and ... sometimes I really wish she was normal (Graff et al. 2012, 186).

The sister's positive and negative emotions regarding having a sibling with DS are so strongly intertwined—she notes “it's so much fun” and “it's really hard” in practically the same breath—thus demonstrating how multifaceted the experience can be. While the sister loves her sibling with DS, she is also left to wonder what their relationship could have been like had her sibling been a TD child (Graff et al. 2012). Most participants claimed the experience to be positive, noting how they loved their siblings' personalities and learned a lot from having them in their family (Graff et al. 2012). Still, almost all of them noted that there were challenges to having a sibling with DS,

mostly in regard to their siblings' behavior and its impact on both them and their family (Graff et al. 2012). Many participants also acknowledged that their siblings' disabilities created financial and emotional stress for their parents (Graff et al. 2012). While about one half of the participants did not wish for any change in their experiences, the other half wished for improvements in their siblings' behavior and abilities to communicate (Graff et al. 2012). A few even felt inadequate themselves, explaining that they wished they could change for the benefit of their sibling with DS (Graff et al. 2012). This study is small in its survey size, but, considering that many prospective parents worry about the impact of DS on the lives of their TD children, the insight it provides—along with the results of Skotko, Levine, and Goldstein's 2011 survey of siblings—can make parents' decisions about what is best for themselves and their families even more complex.

Expanding Beyond the Individual

The decision as to whether to have a DS abortion is deeply personal, but when investigating DS abortions beyond one individual family's course of action, it becomes clear that the greatest dilemma occurs at the societal level. This dilemma sparks a conflict between women's rights and disability rights. Reproductive justice advocates claim that women should have the legal right to have an abortion, regardless of whether the fetus has been diagnosed with a genetic anomaly (Piepmeier 2013).⁴ This matter is essential to the women's rights and reproductive justice movements because, when a couple is considering an abortion, pregnant women are often the ultimate decision maker (Piepmeier 2013). Maggie experienced this responsibility, but she was certainly not alone. Alison Piepmeier, a feminist scholar, conducted interviews with 29 parents of children with DS to learn more about the decision-making process. One interview with a couple revealed that, after receiving the prenatal DS diagnosis, the husband "began identifying the fetus as a child," leaving the woman alone to figure out how they should proceed (Piepmeier 2013, 174). Although her husband would have supported her if she had gotten an abortion, his immediate labeling of the fetus as a child suggested that his decision had been made; deciding whether to have an abortion would thus ultimately be her responsibility (Piepmeier 2013). Another participant described how she knew that, if she chose to have a DS abortion, "she would be alone in her decision because her husband had a very different opinion" (Piepmeier 2013, 174).

Because the burden of having to decide whether to have a DS abortion ultimately falls on the expectant mother, the decision-making process often feels isolating rather than empowering (Piepmeier 2013). Even after women decide what they believe to be the best option for themselves and their families, they are also the ones who must bear any critiques made by family, friends, or even strangers. Some women are accused of being bad parents for having DS abortions, while women who choose to keep their pregnancy after receiving a prenatal DS diagnosis are sometimes blamed for willingly bringing a child with a disability—who some believe will have a life full of suffering—into the world (Reardon 2021; Relf 2014). Because such responsibility falls primarily on women, DS abortions do not just concern the wellbeing of the fetus, nor are they just a human rights issue that equally affects both parents; access to these procedures are also an important women's rights and reproductive justice issue.

Since the right to have an abortion, regardless of whether the fetus has DS, can be an enormous benefit to women's lives and health, advocates in the reproductive justice community

⁴ Reproductive rights and reproductive justice movements have slightly different approaches to abortion rights discussions. The reproductive rights framework often focuses on individual women having the legal right to have an abortion, thereby neglecting the impact that social contexts can have on a person's reproductive decisions. Reproductive justice, on the other hand, recognizes the significant role that society and its inequities can have on these decisions; it sees reproductive freedom as an issue of social justice rather than individual choice (Piepmeier 2013).

are actively fighting state laws that restrict such procedures. Several states have aimed to limit abortions by implementing reason-based abortion bans (see Appendix 1).⁵ Some of these bans prevent women from receiving abortions based on a fetal diagnosis of DS. Reproductive justice advocates argue that governments should not have the power to make reason-based abortion bans because they violate previous Supreme Court cases that prevent governments from restricting abortions done before viability (Donley 2013). While *Roe v. Wade* gave women the right to have an abortion during the first trimester, *Planned Parenthood of Southeastern Pennsylvania v. Casey* somewhat changed this guideline. (Donley 2013) In the ruling of *Planned Parenthood of Southeastern Pennsylvania v. Casey*, the Supreme Court declared that state governments could interfere pre-viability to try to persuade women to avoid abortions, though they could not place an “undue burden” on a woman’s right to have an abortion during this time (Donley 2013). Typically, states legally interfere by mandating waiting periods, requiring that certain information is provided to the woman before the abortion, or establishing certain requirements for the doctors or facilities that provide abortions (Donley 2013). Advocates argue that reason-based abortion laws, like those preventing DS abortions, are then unconstitutional because they completely prevent certain women from having an abortion at any time during their pregnancy, including during the pre-viability period when, according to this Supreme Court case, women should have a right to have an abortion (Donley 2013). Even if states argue the laws are simply a pre-viability “regulation,” they still violate the precedent set in *Planned Parenthood of Southeastern Pennsylvania v. Casey* because, according to the case’s ruling, states and their regulations must still allow women to make the ultimate decision about their abortion pre-viability (Spindelman 2020).

Laws banning abortions done based on genetic abnormalities of the fetus, including DS abortions, are controversial beyond their immediate legal status. Other than being unconstitutional, some claim that these laws can be dangerous to women’s health because they may lead to harmful discussions that question women’s motivations for receiving abortions. Physicians inquiring about women’s reasonings can degrade the trust between women and their physicians, thus harming patient-provider communication (Spindelman 2020). Furthermore, permitting laws that restrict DS abortions because governments deem them morally wrong can establish precedent for making other reason-based abortion bans in the future; eventually, all abortions can be outlawed as morally unacceptable through the argument that no reason for getting an abortion is sufficient (Spindelman 2020).

Even if women have the legal right to choose to have an abortion regardless of genetic anomalies of the fetus, other external pressures often make the decision-making process emotionally toiling. Based on her interviews with parents of children with DS, Piepmeier explains that women facing prenatal DS diagnoses often endure significant pressure from family, friends, and medical professionals when deciding whether to have an abortion (2013). Sometimes, women feel pressed to keep the pregnancy even if they do not want to, but other times, women feel pushed to have an abortion. Some women in the UK have even received 15 offers from their doctors to terminate their pregnancy (Jones 2020). Others have been reminded they can terminate even on the morning they are induced into labor (Jones 2020). This pressure can also come from unexpected sources—for example, family members who have consistently expressed anti-choice beliefs but later offer support for an abortion after hearing about a prenatal DS diagnosis (Piepmeier 2013). Such behavior and uncertainty often worsen the fear women experience while

⁵ “Reason-based abortion bans” refer to laws that prevent certain women from having an abortion based on their reasons for doing so. Currently existing reason-based abortion bans target abortions done on the basis of the sex, race, or genetic abnormality of the fetus (Donley 2013).

contemplating a decision, leading them to feel “as if those around them [have] unpredictable agendas that [have] to be negotiated and manipulated” (Piepmeier 2013, 175).

Tensions Between Disability Rights and Reproductive Justice

Some disability rights activists consider pressures to abort DS pregnancies as evidence that genetics-based abortions are a new kind of eugenics that may lead to a minuscule or nonexistent DS population (see Appendix 2), leading to questions as to how our society sees and treats people with disabilities (Zhang 2020). Many of these activists cite certain countries in Europe as further proof of the possible eugenics movement that is to come—or that has already begun. For example, over the past 10 years, Iceland has had an average of only two to three children born with DS each year (Embassy of Iceland in London 2018). The United States’ estimated DS abortion rate of 75% is somewhat lower than that of several European countries (Reardon 2015). Still, some argue that having a DS abortion can contribute to the discrimination that people with DS experience if their choice is implicitly or explicitly affected by a bias against those with cognitive disabilities (Kaposy 2018). Choosing to keep the pregnancy could help combat ableist perspectives by increasing the number of “self-advocates and natural ambassadors for Down syndrome,” all of whom could help pave the way for those with DS to have better lives, greater social inclusion, and improved housing and employment (Kaposy 2018, 121).

Considering how some women, particularly those in Europe, may face pressure and even encouragement to have a DS abortion, it is no surprise that some disability rights advocates are calling for change. Expectant parents receiving prenatal DS diagnoses are sometimes given biased or outdated information from doctors, and medical professionals repeatedly pester some mothers with offers to abort a fetus diagnosed with DS (Jones 2020). Women may also experience an insistence to have an abortion from family members, partners, or even strangers. After sharing her experience having a daughter with DS on the *New York Times* website, Piepmeier received many comments shaming her choice to not have an amniocentesis to screen for DS (Piepmeier 2013).⁶ Commenters wrote of the pain and suffering she was purposefully inflicting on her child, of the sin she was committing by having a child with DS and thereby burdening her other children and society as a whole (Piepmeier 2013). The staunch opposition that Piepmeier and other women face when considering or wanting to keep a pregnancy after receiving a DS diagnosis gives insight into the discrimination that people with disabilities face every day and why some people oppose DS abortions.

One example of a campaign against DS abortions occurred in the UK in 2021, with the head of the movement being Heidi Crowter, a woman with DS. In the UK, women have the right to have an abortion until 24 weeks of gestation, but in the case of DS pregnancies, it is legal to have an abortion up until the birth of the baby (Woods 2021). Heidi lobbied along with Máire Lea-Wilson, a mother of a son with DS, for that law to change, saying that the allowance for DS pregnancies is discriminatory because it treats these pregnancies differently than others (Down’s syndrome 2021). Heidi, Máire, and even the UN Committee on the Rights of Persons with Disabilities argue that the law suggests that the life of a TD person is more valuable than the life of a person with disabilities (Pring 2021). Despite their arguments, the abortion law was ultimately upheld (Pring 2021).

⁶ An amniocentesis is a medical procedure in which amniotic fluid is removed from the uterus as treatment for medical conditions or to be tested. Test results can be used to diagnose the fetus with genetic disorders, such as DS, and other health issues. Unlike the MaterniT21 test that Maggie received, an amniocentesis carries risks, some of which include miscarriage and infection (Mayo Clinic Staff 2020).

Heidi's efforts generated a mixed response even amongst the DS and disability rights communities, demonstrating the complexity surrounding the conflicting perspectives between disability rights and the women's rights and reproductive justice movements (Pring 2021). Some community members, like a disabled collective known as Sisters of Frida, were reluctant to weigh in at all. Instead, the collective acknowledged the difficult conflict the case creates between disability rights and women's rights (Pring 2021). Others, like a disability rights activist named Simone Aspis, praised Crowter's work, claiming that the discrimination seen in the UK's abortion law also justifies limited access to inclusive living and working conditions for individuals with disabilities (Pring 2021). Even others in the disability rights community held a different point of view and agreed with the ruling. Scholars of the disability rights community argued that late abortions are usually undesired and occur mostly because women do not receive diagnoses until past the 24-week mark; the law may also give women with less access to healthcare the ability to still get an abortion if they choose to do so (Pring 2021).

Such debates extend beyond the UK; indeed, during the same year that Crowter challenged the UK abortion law, a similar clash occurred in North Carolina over House Bill 453, or the Human Life Nondiscrimination Act/No Eugenics Bill (Hoban 2021). Framed as a protection of disability rights, the bill would prohibit physicians from performing any abortions done due to the "presence or presumed presence of Down syndrome" (Hoban 2021, n.p.). As with Crowter's work in the UK, House Bill 453 resulted in a wide range of responses, even from parents of children with DS and disability organizations (Hoban 2021). For example, some parents of children with DS argued that families should have the option to choose what they believe is right for them, but other parents brought their children with DS to the state legislature to testify in support of the bill (Hoban 2021). Few state disability organizations chose to comment on the bill; one group, The Arc of North Carolina, maintained neutrality, and another, Disability Rights North Carolina, spoke in opposition of the bill, criticizing its limitation on women's bodily autonomy.

The conflict between disability rights and women's rights remains complex no matter where such disputes occur. These highly nuanced perspectives make it extremely difficult to determine what the right course of action may be. Maggie and other pregnant people who receive prenatal DS diagnoses may not directly grapple with these large-scale issues when they are making their own reproductive decisions—their individual course of action may be more greatly impacted by factors such as health insurance, social support, and abortion laws in their state. Still, the consequences of this debate certainly affect those who receive prenatal DS diagnoses. Who gets to decide how to proceed? Should it be state governments, the federal government, medical professionals, or even religious leaders? Or should it be women and people with disabilities? How can these groups agree when their differing perspectives are central to waging the war revolving around DS abortions? What knowledge and experience are involved parties using to make this decision, and are they all of equal significance? After all, all the groups involved have unique circumstances affecting their decisions and are faced with very different potential consequences—are they even facing the same choices?

References

- Abboud, Carolina J. 2017. "Doe v. Bolton (1973) | The Embryo Project Encyclopedia." <https://embryo.asu.edu/pages/doe-v-bolton-1973> (Accessed August 29, 2022).
- American Civil Liberties Union. "Access Denied: Origins of the Hyde Amendment and Other Restrictions on Public Funding for Abortion." <https://www.aclu.org/other/access-denied-origins-hyde-amendment-and-other-restrictions-public-funding-abortion> (Accessed August 29, 2022).
- The American College of Obstetricians and Gynecologists. "Having a Baby After Age 35: How Aging Affects Fertility and Pregnancy." *ACOG*. <https://www.acog.org/en/womens-health/faqs/having-a-baby-after-age-35-how-aging-affects-fertility-and-pregnancy> (Accessed June 12, 2022).
- American Psychological Association. 2017. "Individuals with Disabilities Education Act (IDEA)." <https://www.apa.org/advocacy/education/idea> (Accessed April 7, 2022).
- Baker, Carrie N. 2020. "The History of Abortion Law in the United States." <https://www.ourbodiesourselves.org/book-excerpts/health-article/u-s-abortion-history/> (Accessed May 4, 2022).
- Boston Children's Hospital. "Down Syndrome." <https://www.childrenshospital.org/conditions/down-syndrome> (Accessed April 4, 2022).
- Bourke, Jenny, Bernadette Ricciardo, Ami Bebbington, Karina Aiberti, Peter Jacoby, Paula Dyke, Michael Msall, Carol Bower, and Helen Leonard. 2008. "Maternal Physical and Mental Health in Children with Down Syndrome." *The Journal of pediatrics* 153 (3): 320–26. doi: 10.1016/j.jpeds.2008.02.047 (Accessed April 4, 2022).
- Brown, Roy, Janet Taylor, and Brian Matthews. 2001. "Quality of Life - Ageing and Down Syndrome." *Down Syndrome Research and Practice* 6 (3): 111–16. doi: 10.3104/case-studies.101 (Accessed June 15, 2022).
- Burns, Julie. 2020. "Evolving Perspectives of Disability: Mothers' Stories of A Trisomy 21 Diagnosis." Ph.D. Union Institute and University. <https://www.proquest.com/pqdtglobal/docview/2572593177/abstract/C196A63E198148E0PQ/1> (Accessed March 6, 2022).
- Care.com. 2022. "Special Needs Care for Adult Children: Cost of Care." <https://www.care.com/c/special-needs-care-for-adult-children-cost-of-care/> (Accessed April 4, 2022).
- CBS News. *A Mother's Story of Down Syndrome*. 2015. Video. <https://www.youtube.com/watch?v=j3GBEz04gHg> (Accessed March 16, 2022).

- CDC. 2018. "Hospital Costs and Length of Stay Among Children with Down Syndrome." <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/features/hospital-cost-downsyndrome.html> (Accessed April 4, 2022).
- Chappell, Bill. 2016. "Supreme Court Rejects North Dakota's Bid To Save Strict Abortion Law." *NPR*, <https://www.npr.org/sections/thetwo-way/2016/01/25/464311731/supreme-court-rejects-north-dakota-s-bid-to-save-strict-abortion-law> (Accessed April 3, 2022).
- Claire. 2020. "I Had an Abortion after I Found out My Baby Had Down's Syndrome." *Metro*, <https://metro.co.uk/2020/11/24/i-had-an-abortion-after-i-found-out-my-baby-had-downs-syndrome-13620640/> (Accessed April 8, 2022).
- Coffey, Laura. 2021. "Down Syndrome Stories: 21 Things Parents Wish They Knew." *TODAY*, <https://www.today.com/series/things-i-wish-i-knew/down-syndrome-stories-21-things-parents-wish-they-knew-t150473> (Accessed April 7, 2022).
- Donley, Greer. 2013. "Does the Constitution Protect Abortions Based on Fetal Anomaly?: Examining the Potential for Disability-Selective Abortion Bans in the Age of Prenatal Whole Genome Sequencing." *Michigan Journal of Gender & Law* 20 (2): 291–328. doi: 10.36641/mjgl.20.2.does (Accessed March 7, 2022).
- Down Syndrome Pregnancy. "Emotional Impact." <http://downsyndromepregnancy.org/emotional-impact/> (Accessed April 4, 2022).
- "Down's Syndrome: Abortion Case Heads to High Court." 2021. *BBC News*, <https://www.bbc.com/news/uk-england-56982646> (Accessed April 9, 2022).
- Eligon, John, and Erik Eckholm. 2013. "New Laws Ban Most Abortions in North Dakota." *The New York Times*, <https://www.nytimes.com/2013/03/27/us/north-dakota-governor-signs-strict-abortion-limits.html> (Accessed April 3, 2022).
- Embassy of Iceland in London. 2018. "Facts about Down's Syndrome and Pre-Natal Screening in Iceland." <https://www.government.is/diplomatic-missions/embassy-article/2018/03/26/Facts-about-Downs-syndrome-and-pre-natal-screening-in-Iceland/> (Accessed April 9, 2022).
- Gale. 2018. "Abortion." *Gale*. <https://www.gale.com/open-access/abortion> (Accessed April 3, 2022).
- Global Down Syndrome Foundation. 2019. "Congenital Heart Defects and Down Syndrome: What Parents Should Know." *Global Down Syndrome Foundation*. <https://www.globaldownsyndrome.org/congenital-heart-defects-syndrome-parents-know/> (Accessed October 26, 2022).

- de Graaf, Gert, Frank Buckley, and Brian G. Skotko. 2021. "Estimation of the Number of People with Down Syndrome in Europe." *European Journal of Human Genetics* 29 (3): 402–10. doi: 10.1038/s41431-020-00748-y (Accessed April 12, 2022).
- Graff, Carol, Barbara Mandleco, Tina Taylor Dyches, Catherine R. Coverston, Susanne Olsen Roper, and Donna Freeborn. 2012. "Perspectives of Adolescent Siblings of Children With Down Syndrome Who Have Multiple Health Problems." *Journal of Family Nursing* 18 (2): 175–99. doi: 10.1177/1074840712439797 (Accessed May 1, 2022).
- Guttmacher Institute. 2016a. "Abortion Bans in Cases of Sex or Race Selection or Genetic Anomaly." <https://www.guttmacher.org/state-policy/explore/abortion-bans-cases-sex-or-race-selection-or-genetic-anomaly> (Accessed April 3, 2022).
- . 2016b. "State Facts About Abortion: North Dakota." <https://www.guttmacher.org/fact-sheet/state-facts-about-abortion-north-dakota> (Accessed April 3, 2022).
- Hill, Erica. 2012. "Early Prenatal Test Raises Ethical Questions - CBS News." *CBS News*, <https://www.cbsnews.com/news/early-prenatal-test-raises-ethical-questions/> (Accessed March 16, 2022).
- Hoban, Rose. 2021. "In Debate over Down Syndrome/Abortion Bill, Disability Groups Struggle with How to Respond." *North Carolina Health News*, <http://www.northcarolinahealthnews.org/2021/06/08/disability-groups-struggle-to-respond-to-latest-abortion-bill/> (Accessed April 9, 2022).
- Jones, Charlie. 2020. "Down's Syndrome: 'In All Honesty We Were Offered 15 Terminations.'" *BBC*, <https://www.bbc.com/news/uk-england-beds-bucks-herts-51658631> (Accessed April 9, 2022).
- Kageleiry, Andrew, David Samuelson, Mei Sheng Duh, Patrick Lefebvre, John Campbell, and Brian G. Skotko. 2017. "Out-of-Pocket Medical Costs and Third-Party Healthcare Costs for Children with Down Syndrome." *American Journal of Medical Genetics Part A* 173 (3): 627–37. doi: 10.1002/ajmg.a.38050 (Accessed April 4, 2022).
- Kaposy, Chris. 2018. *Choosing Down Syndrome: Ethics and New Prenatal Testing Technologies*. Cambridge, Massachusetts: The MIT Press.
- Lee, Anna, George Knafl, Kathleen Knafl, and Marcia Van Riper. 2021. "Quality of Life in Individuals with Down Syndrome Aged 4 to 21 Years." *Child: Care, Health and Development* 47 (1): 85–93. doi: 10.1111/cch.12815 (Accessed April 7, 2022).
- Lino, Mark. 2020. "The Cost of Raising a Child." <https://www.usda.gov/media/blog/2017/01/13/cost-raising-child> (Accessed April 4, 2022).

- Mayo Clinic Staff. 2020a. “Amniocentesis.” <https://www.mayoclinic.org/tests-procedures/amniocentesis/about/pac-20392914> (Accessed August 26, 2022).
- . 2020b. “Down Syndrome.” <https://www.mayoclinic.org/diseases-conditions/down-syndrome/symptoms-causes/syc-20355977> (Accessed April 4, 2022).
- National Down Syndrome Society. n.d.-a. “Down Syndrome Facts.” <https://www.ndss.org/about-down-syndrome/down-syndrome-facts/> (Accessed March 16, 2022).
- . n.d.-b. “What Is Down Syndrome?” <https://www.ndss.org/about-down-syndrome/down-syndrome/> (Accessed March 16, 2022).
- . n.d.-c. “Early Intervention.” <https://www.ndss.org/resources/early-intervention> (Accessed August 29, 2022).
- Piepmeyer, Alison. 2013. “The Inadequacy of ‘Choice’: Disability and What’s Wrong with Feminist Framings of Reproduction.” *Feminist Studies* 39 (1): 159–86. <https://www.jstor.org/stable/23719307> (Accessed March 7, 2022).
- “Planned Parenthood of Southeastern Pennsylvania v. Casey.” <https://www.oyez.org/cases/1991/91-744> (Accessed April 3, 2022).
- Pring, John. 2021. “Mixed Response from Disabled Activists to Heidi Crowter Abortion Case Ruling.” *Disability News Service*, <https://www.disabilitynewsservice.com/mixed-response-from-disabled-activists-to-heidi-crowter-abortion-case-ruling/> (Accessed April 9, 2022).
- Reardon, Maggie. 2021. “It’s World Down Syndrome Day.” https://www.facebook.com/maggie.reardon.31/?show_switched_toast=0&show_invite_to_follow=0&show_switched_tooltip=0&show_podcast_settings=0&show_community_transition=0&show_community_review_changes=0 (Accessed March 14, 2022).
- Reardon, Marguerite. 2015. “‘I Didn’t Know I Would Be Able to Love Her the Way I Do’: A Mother’s Story of Down Syndrome.” *CBS News*, <https://www.cbsnews.com/news/down-syndrome-mothers-story/> (Accessed March 10, 2022).
- Relf, Gillian. 2014. “‘I Wish I’d Aborted the Son I’ve Spent 47 Years Caring for’: It’s a Shocking Admission - but Read before You Judge.” *DailyMail.com*, <https://www.dailymail.co.uk/femail/article-2803834/I-wish-d-aborted-son-ve-spent-47-years-caring-s-shocking-admission-read-judge.html> (Accessed March 6, 2022).
- Richardson, Chinué Turner, and Elizabeth Nash. 2015. “Misinformed Consent: The Medical Accuracy of State-Developed Abortion Counseling Materials.” *Guttmacher Institute*. <https://www.guttmacher.org/gpr/2006/10/misinformed-consent-medical-accuracy-state-developed-abortion-counseling-materials> (Accessed October 26, 2022).

- Rutter, Sarah. 2019. "Down's Syndrome." *University of Hertfordshire*.
<http://www.intellectualdisability.info/conditions-associated-with-intellectual-disability/articles/downs-syndrome> (Accessed October 26, 2022).
- Saha, Sayoni, Eric Doran, Kathryn E. Osann, Christy Hom, Nina Movsesyan, Diana D. Rosa, Anne Tournay, and Ira T. Lott. 2014. "Self-Concept in Children with Down Syndrome." *American Journal of Medical Genetics Part A* 164 (8): 1891–98. doi: 10.1002/ajmg.a.36597 (Accessed April 7, 2022).
- Shimabukuro, Jon. 2022. *Abortion: Judicial History and Legislative Response*. Congressional Research Service. <https://sgp.fas.org/crs/misc/RL33467.pdf> (Accessed April 3, 2022).
- Skotko, Brian G., Susan P. Levine, and Richard Goldstein. 2011a. "Having a Brother or Sister with Down Syndrome: Perspectives from Siblings." *American Journal of Medical Genetics Part A* 155 (10): 2348–59. doi: 10.1002/ajmg.a.34228 (Accessed April 7, 2022).
- . 2011b. "Having a Son or Daughter with Down Syndrome: Perspectives from Mothers and Fathers." *American Journal of Medical Genetics Part A* 155 (10): 2335–47. doi: 10.1002/ajmg.a.34293 (Accessed April 7, 2022).
- . 2011c. "Self-Perceptions from People with Down Syndrome." *American Journal of Medical Genetics Part A* 155 (10): 2360–69. doi: 10.1002/ajmg.a.34235 (Accessed March 5, 2022).
- Spindelman, Marc. 2020. "Embracing Casey: June Medical Services L.L.C. v. Russo and the Constitutionality of Reason-Based Abortion Bans." *The Georgetown Law Journal* 109: 115–41. <https://www.law.georgetown.edu/georgetown-law-journal/glj-online/109-online/embracing-casey/> (Accessed March 7, 2022).
- Treussard, Suzanne. 2014. "Aborting My Baby Oscar Was the Kindest Thing I Could Do for Him." *Mail Online*, <https://www.dailymail.co.uk/femail/article-2787202/Aborting-baby-Oscar-kindest-thing-I-Woman-agonising-decision-end-child-s-life-discovering-Down-s-syndrome.html> (Accessed May 1, 2022).
- Woods, Rebecca. 2021. "Down's Syndrome Campaigner Heidi Crowter on Marriage and Loving Life." *BBC*, <https://www.bbc.com/news/uk-england-coventry-warwickshire-57089602> (Accessed April 9, 2022).
- Zhang, Sarah. 2020. "The Last Children of Down Syndrome." *The Atlantic*, <https://www.theatlantic.com/magazine/archive/2020/12/the-last-children-of-down-syndrome/616928/> (Accessed April 8, 2022).

Appendix A: States' Current Reason-Based Abortion Bans (Guttmacher Institute 2016a)

STATE	ABORTION BANS IN CASES OF SEX OR RACE SELECTION OR GENETIC ANOMALY		
	PROHIBITS ABORTION IN CASE OF:		
	Sex Selection	Race Selection	Genetic Anomaly
Arizona	X	X	▽
Arkansas	X		▽
Illinois	▼*		
Indiana	▼	▼	▼
Kansas	X		†
Kentucky	▽	▽	▽
Louisiana			▽
Minnesota			†
Mississippi	X	X	X
Missouri	X	X	X
North Carolina	X		
North Dakota	X		X
Ohio			‡
Oklahoma	X		†
Pennsylvania	X		
South Dakota	X		X
Tennessee	X	X	X
Utah			‡
TOTAL	11	4	6

▼ Enforcement permanently enjoined by court order; policy not in effect.

▽ Law is temporarily enjoined, policy is not in effect.

* Illinois's ban applies after viability; in 1993, a federal court enjoined the portion of the bill that applies before viability.

† Minnesota and Oklahoma require counseling on perinatal hospice services if an abortion is sought due to a lethal fetal abnormality. Arizona requires counseling about perinatal hospice services if an abortion is sought due to a lethal fetal abnormality, as well as counseling on outcomes for those living with the condition that the fetus is diagnosed with if the abortion is sought for a nonlethal fetal condition. Kansas requires counseling on perinatal hospice services before all abortions.

‡ Utah's ban will only take effect if a court decision allows states to ban abortion in these cases.

Appendix B: Effects of DS Abortions on Live Birth Prevalence of People with DS (de Graaf, Buckley, and Skotko 2021)

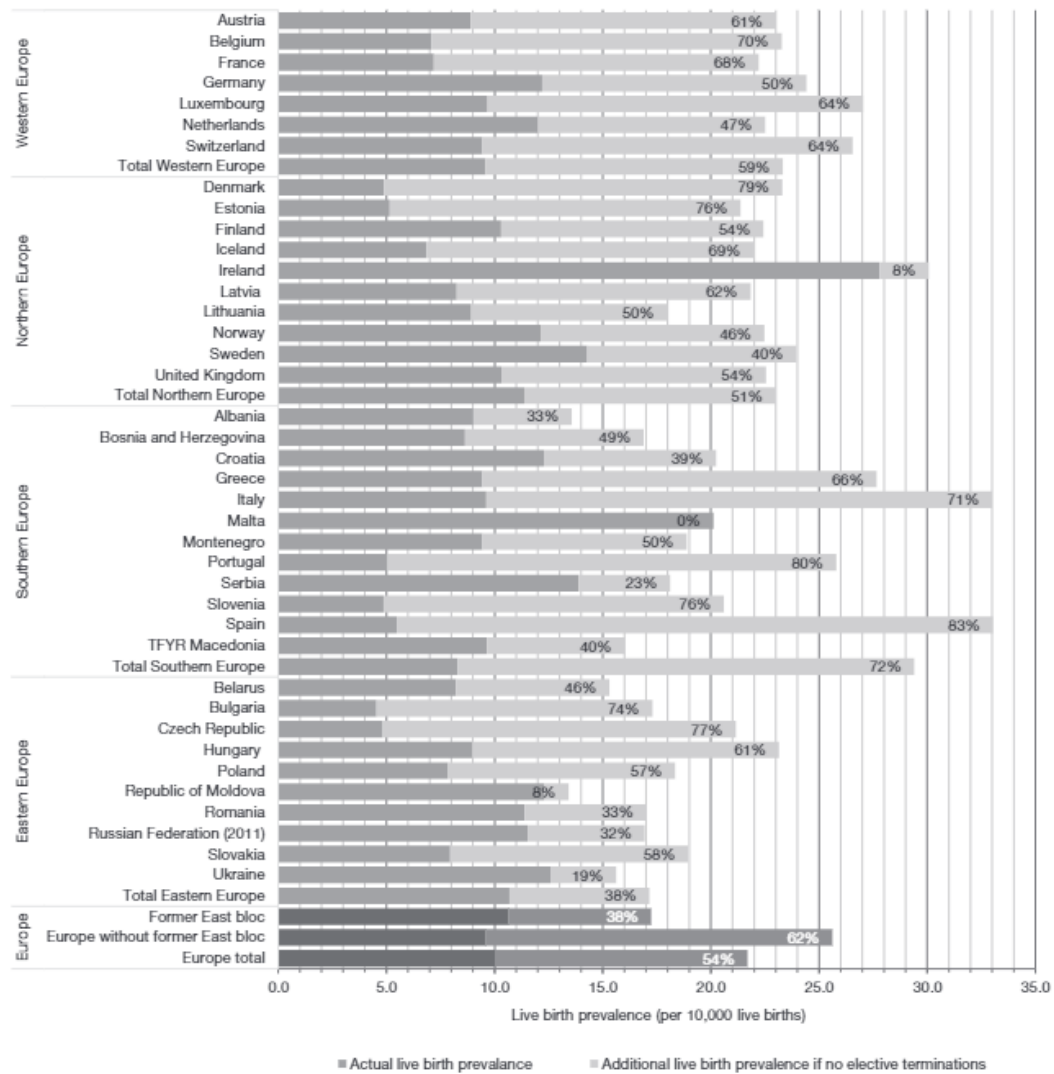


Fig. 1 Live birth prevalence estimates of people with Down syndrome (DS) per 10,000 live births (2011–2015) and the effect of elective terminations. Percentages denote the reduction due to DS-specific elective terminations.