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Down Syndrome and Social Capital: Assessing the Costs of Selective Abortion

Item Type	Bicameral Minority Staff Report
Download date	2026-06-10 21:54:21
Link to Item	https://hdl.handle.net/20.500.14300/3363

Down Syndrome and Social Capital: Assessing the Costs of Selective Abortion

SCP REPORT NO. 2-22 | MARCH 2022

social capital project

A project of the Joint Economic Committee – Republicans | Ranking Member Mike Lee (R-UT)
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KEY POINTS

- All people with Down syndrome are intrinsically and immeasurably valuable. In addition, people with Down syndrome are happy with their lives and make their families and communities better off.
- Medical advancements have helped increase life expectancy of people with Down syndrome from about 10 years in the 1960s to over 50 years in 2020 according to JEC Republican estimates, but at the same time have led to expanded screening during pregnancy that opens the door to a rise in selective abortions.
- JEC Republicans estimate that absent selective abortion, 80 percent more babies with Down syndrome would be born each year and that the Down syndrome population would be 217,000 people greater in 50 years, an *increase* which is greater than the current Down syndrome population.

INTRODUCTION

World Down Syndrome Day is an important opportunity to reflect on the lives and contributions of an often overlooked group of Americans. Misconceptions about people with Down syndrome lead to a disproportionate number of diagnosed children being aborted. It is estimated that [60 percent to 90 percent](#)¹ of children diagnosed with Down syndrome are aborted in the U.S., compared to [18 percent](#) of all pregnancies ending in abortion.²

These issues are even more important this year, as Americans wait for the Supreme Court to rule on *Dobbs v. Jackson Women's Health Organization*. *Dobbs* is expected to challenge the precedent set in *Roe v. Wade* and later cases, and if overturned could change the legal status of abortion within the United States. While abortion impacts all kinds of Americans, few populations are affected as much as those with Down syndrome.

A likely driver of the difference in abortion rates of people with Down syndrome and the general population is noninvasive prenatal screenings, which were [introduced in 2011](#) and have become increasingly widespread in the years since.³ Noninvasive prenatal tests are non-diagnostic but screen for chromosomal disorders such as Down syndrome and Turner's syndrome. Compared to [other](#) prenatal screening tests,⁴ the accuracy of screening for Down syndrome is relatively high with a low false negative rate.⁵ However, these prenatal tests do not address the extent of the disability or the symptoms that the baby might have. Misconceptions about Down syndrome and a lack of counseling following a positive screening likely leads to more children being aborted than otherwise would have been had the parents had better information. As testing becomes [more prevalent](#), even more abortions of children with Down syndrome will likely occur.⁶

This report evaluates the impact of selective abortion by estimating the additional number of babies with Down syndrome who would be born each year absent selective abortion, and how this would affect the population of Americans with Down syndrome over time. Weighing the impact of selective abortion is especially important given the incalculable intrinsic value of all human life. For individuals with Down syndrome, it is particularly important to understand that they have high life satisfaction, improve the lives of their family members, and contribute to their communities through work and other activities. Recognizing the value of people with Down syndrome is more important than ever given [medical advancements](#) that on the one hand have led to a surge in life expectancy for Americans with Down syndrome, and on the other hand have led to expanded screening during pregnancy that opens the door to a rise in selective abortions.⁷

The report proceeds by describing the population of people with Down syndrome and their rise in life expectancy over the past several decades, documenting their contributions to society, and providing novel estimates of the additional births and higher population of Americans with Down syndrome if selective abortion were ended.

POPULATION OF AMERICANS WITH DOWN SYNDROME AND THEIR RISE IN LIFE EXPECTANCY

Down syndrome is a genetic [chromosomal disorder](#) that is caused by an abnormal cell division that results in a baby being born with an extra chromosome.⁸ Down syndrome can cause various physical and mental [challenges](#) such as delayed learning development and heart problems.⁹ The extent of disability varies by individual, and some people with Down syndrome may only have minor physical or mental disabilities. The exact origin of the abnormal cell division that causes Down syndrome is still [not fully known](#), though a higher maternal age is associated with a higher prevalence of Down syndrome.¹⁰

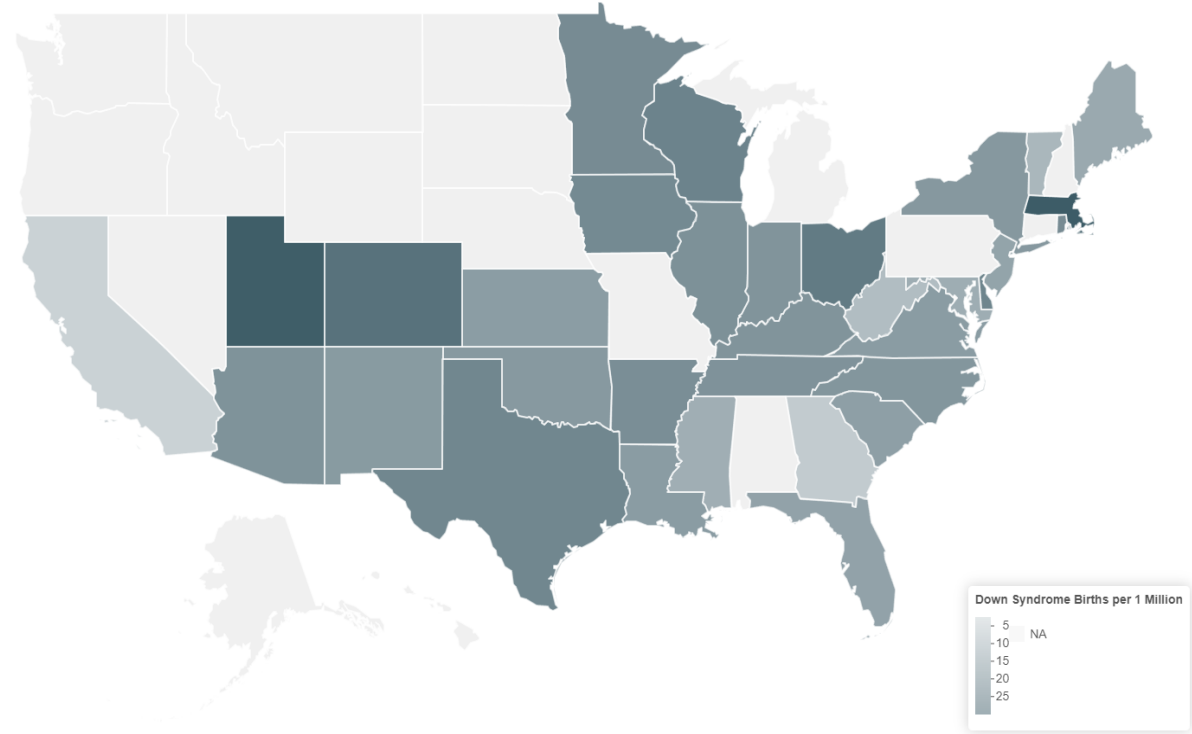
Population

The number of babies born with Down syndrome each year grew by [30 percent](#) between 1979 and 2003, although this upward trend is unlikely to continue due to the rise in noninvasive prenatal testing and selective abortion.¹¹ In countries where prenatal testing is widespread and selective abortion is an accepted practice, such as [Iceland](#), nearly 100 percent of pregnancies that receive a positive test for Down syndrome are aborted.¹² In the U.S. it is currently [estimated](#) that about 1 in every 700 births in the United States are to a baby with Down syndrome, which amounts to around 6,000 babies being born with Down syndrome each year.¹³

Because there is no [population-based registry](#) for people with Down syndrome in the United States, studies must estimate their population.¹⁴ One [study](#) uses live birth data and survival rates by age to estimate that there were 206,366 people living with Down syndrome in the United States as of 2010.¹⁵ As attitudes and behaviors change and prenatal testing becomes more prevalent, the need for better data on those with Down syndrome in the United States becomes even more important. Accurate data on the demographics of people with Down syndrome would allow healthcare providers to more accurately monitor trends in the Down syndrome population and address disparities in their health outcomes.

While state-level population estimates are not available, the number of Down syndrome live births per 1 million people by state is shown in Figure 1.

Figure 1. Annualized Number of Down Syndrome Births per 1 Million People by State, 2014 to 2018



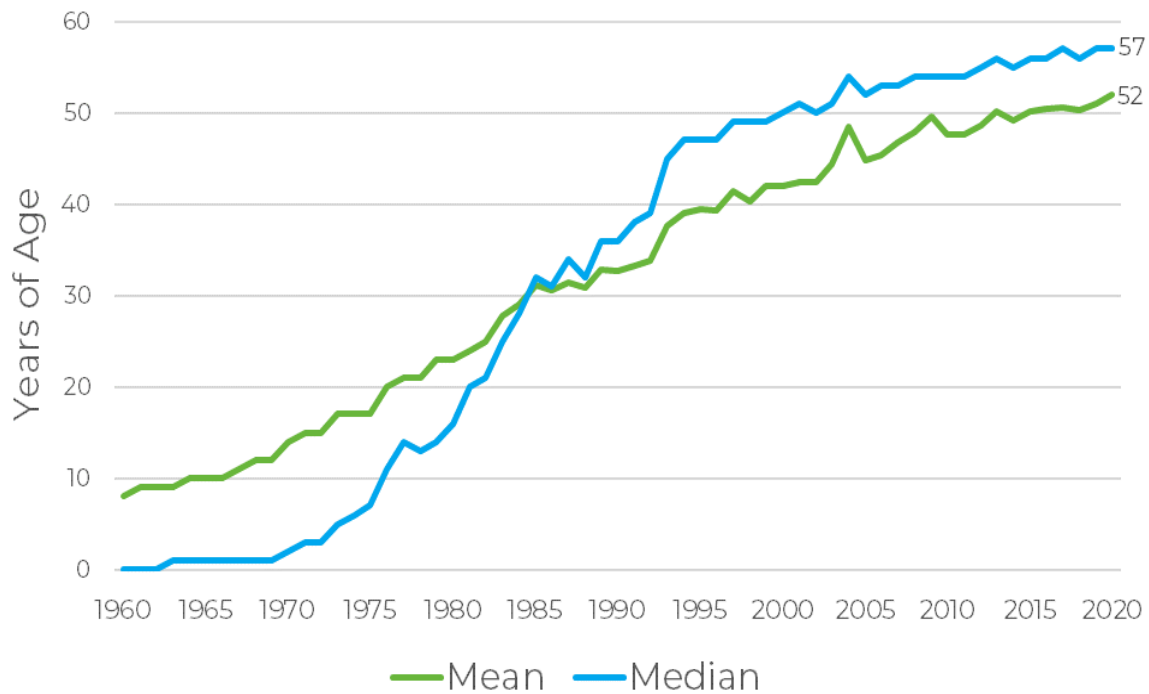
Source: JEC Calculations. Data collected from [National Birth Defects Prevention Network](#).
Notes: Data were only available for 34 states. Calculations for number of Down syndrome births per 1 million people by state were made by using data that tracks Down syndrome birth counts by state over a range of years, typically 2014 to 2018 for most states. After calculating the number of Down syndrome births per year by state, these annualized values were divided by the state population for the most recent year Down syndrome data were collected. The resulting value is multiplied by 1 million to obtain the number of Down syndrome births per 1 million people by state.

This map highlights the wide range of Down syndrome birth prevalence by state and suggests where the Down syndrome population is likely to be higher. The number of Down syndrome births in states that reported data ranged from 2.6 births per million in California to almost 30 births per million in Utah and Massachusetts. The large variation in Down syndrome birth prevalence by state likely reflects variation in overall fertility, maternal ages, and the level of community and local support. For example, community organizations like the [Utah Down Syndrome Foundation](#) provide support to individuals with Down syndrome and their families. They provide education and outreach for new and expecting parents of babies with Down syndrome and offer community activities for children with Down syndrome. These charities are a vital form of social capital and play an indispensable role in supporting the Down syndrome community.

Rise in Life Expectancy

Misconceptions and a lack of community understanding of people with Down syndrome have historically played an adverse role in both their health and overall quality of life. In the 1960s the [average life expectancy](#) for a person with Down syndrome was only about 10 years, and more than half of all deaths were among children under the age of two.¹⁶ By 2020, life expectancy jumped to around 52 years, and half of deaths occurred in individuals aged 57 or higher.¹⁷ Figure 2 displays the mean and median age of death for those with Down syndrome since 1960.

Figure 2. Mean and Median Age of Death for Americans With Down Syndrome, 1960-2020



Source: JEC calculations for years 1999-2020 using [CDC Wonder](#) data; data for years 1960 to 1998 derived from Presson et al.¹⁸
 Notes: We extract from CDC Wonder the number of yearly Down syndrome deaths from 1999-2020 by age. Using this information, we are able to calculate the mean and median age of death of people with Down syndrome in a given year. For years 1960-1998 values shown in Figure 2 are obtained from Presson et al. [Current Estimate of Down Syndrome Population Prevalence in the United States](#). Comparisons in results from our methodology and that of Presson et al. are noted in Appendix A.

Before the 1980s, the majority of people with Down syndrome were [institutionalized and](#) lacked proper healthcare and educational opportunities which led to a significantly worse quality of life and shorter lifespan.¹⁹ For example, it was generally believed that children with Down syndrome were incapable of learning to read or write. Experts now recognize that the [vast majority](#) of people with Down syndrome are able to read, write, and go to school;²⁰ some have gone on to [graduate](#) from college.²¹ As the medical community continues to better understand the special needs of people with Down syndrome and tailored resources for them continue to expand, more advancements are likely in health and educational outcomes.

CONTRIBUTIONS TO SOCIETY

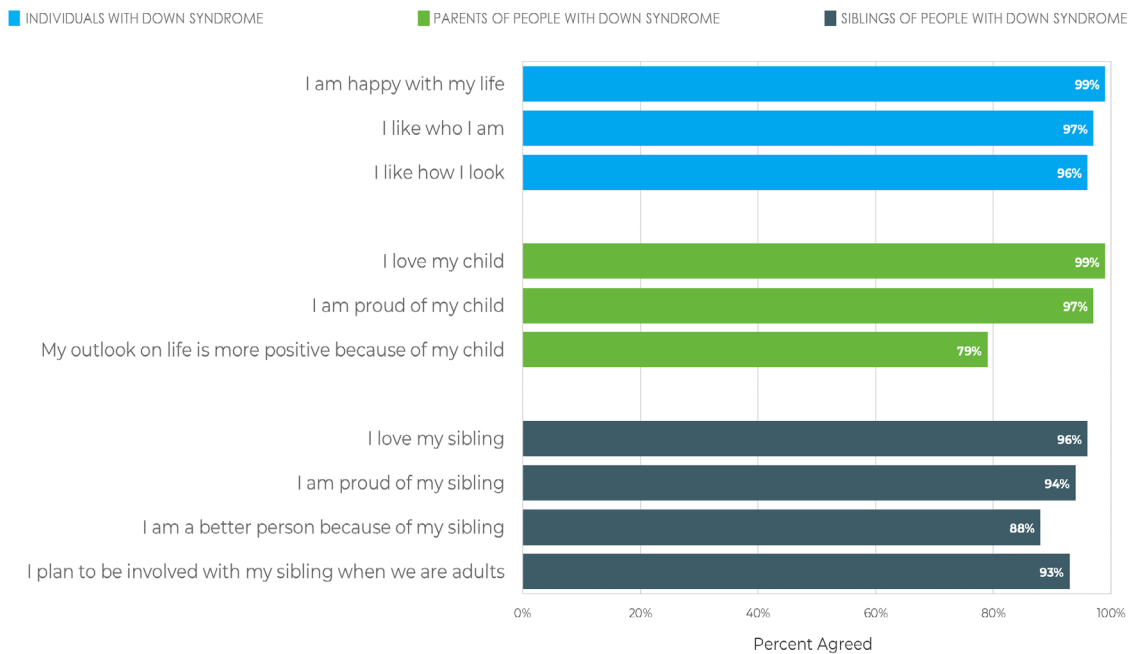
All people with Down syndrome are intrinsically and immeasurably valuable. While the inherent value of people with Down syndrome is not affected by their contributions to society or their perceived quality of life, it is nonetheless important to document that these contributions are substantial.

Personal and Family Contributions

Americans with Down syndrome generally report extremely high life satisfaction. A [survey](#) of Americans with Down syndrome ages 12 and older found that 99 percent indicate that they are happy with their lives.²² Additionally, 97 percent report liking who they are and 96 percent report liking how they look. These responses are consistent regardless of the respondent's home situation or education, indicating people with Down syndrome live fulfilling and happy lives regardless of the extent of their disability.

Parents and siblings of individuals with Down syndrome also indicate having positive experiences from having a relationship with someone who has Down syndrome. In one [survey](#), 99 percent of parents report they love their child with Down syndrome, 97 percent are proud of them, and 79 percent report their outlook on life is more positive because of their child with Down syndrome.²³ These sentiments are also observed in the siblings of children with Down syndrome. A similar [survey](#) finds 96 percent of siblings have affection towards their brother or sister with Down syndrome and 94 percent express feelings of pride towards their sibling.²⁴

Figure 3. Results from Life Satisfaction Surveys, United States, 2011



Sources: Skotko BC, Levin SP, Goldstein R. "Having a son or daughter with Down syndrome: Perspectives from mothers and fathers;"²⁵ Skotko BC, Levin SP, Goldstein R. "Having a brother or sister with Down syndrome: perspectives from siblings".²⁶

Community Contributions

People with Down syndrome also make significant contributions to their communities through work. Employment can provide people with Down syndrome the ability to build social relationships, develop skills, become more independent, and contribute to their own financial needs. Hiring people with Down syndrome allows employers to diversify their workforce and bring in new perspectives. For example, the vast majority of [managers](#) report that interacting with employees with Down syndrome made them more empathetic and improved their conflict management skills.²⁷

Despite many people with Down syndrome being able and willing to work, only a small percent have full time paid employment. No extensive employment data exist for people with Down syndrome, but [studies](#) suggest that they are employed at significantly lower rates than the general population.²⁸ According to a [study](#) on employment and choice-making for adults with Down syndrome from 2011-2013,²⁹ 46 percent have some form of employment compared to [70 percent](#) of working age adults in the general population.³⁰ Sixteen percent of Americans with Down syndrome are employed in paid community jobs and the other 30 percent participate in paid facility work or sheltered employment. [Sheltered employment](#)

is supervised employment where those with disabilities are paid a set amount for completing tasks such as sorting mail or answering phone calls.³¹ These jobs typically have fewer hours than a traditional job and generally pay less than the federal minimum wage.

Misconceptions about the abilities of people with Down syndrome may adversely affect the extent to which they are employed in the community. Many people with Down syndrome are capable of working in a [multitude](#) of different industries such as food service, retail, and customer service.³² At a time when there have been over a million [job openings](#) in industries such as accommodation and food services as of December 2021, people with Down syndrome are underutilized and may be able to fill some of these positions.³³ People with Down syndrome are often [highly motivated](#) and with proper training are able to become valuable contributors in the workforce.³⁴ Companies should consider expanding job training and employment opportunities for people with Down syndrome especially at a time when there are significant job openings in industries in which people with Down syndrome are capable of working.

IMPACT OF ENDING SELECTIVE ABORTION ON THE DOWN SYNDROME POPULATION

People with Down syndrome are indispensable members of our communities and quantifying the impact of selective abortion on this population can help Americans better understand the costs of selective abortion. We first estimate the effect of ending selective abortion on the number of births of babies with Down syndrome each year, and then we estimate how much larger the population would be in future years as a result.

Birth Estimate

We estimate there would be 4,778 additional babies with Down syndrome born each year in the absence of selective abortion. We arrive at this estimate by first adjusting the most recent estimate of [6.37 million pregnancies](#) in the U.S. population in 2009 by the percent change in the number of live births from 2009 to 2019, the most recent year not affected by the COVID-19 pandemic.³⁵ On the basis of this adjustment, we estimate that there were 5.74 million pregnancies in 2019. During the first trimester—before prenatal tests for Down syndrome are typically administered—13.6 percent of pregnancies end in miscarriage.³⁶ [Eighteen percent](#) of pregnancies are terminated due to abortion, overwhelmingly during the first trimester.³⁷ This results in 4.09 million pregnancies that make it to the end of the first trimester.³⁸

It is estimated that [72 percent](#) of pregnancies in the United States receive a prenatal test.³⁹ Of those that receive a prenatal test, only a certain amount will correctly indicate Down syndrome. [A study](#) found that out of 100,000 noninvasive prenatal tests one can expect 417 positive cases of Down syndrome to be

detected with 94 false positives.⁴⁰ Subtracting the false positives from the number of positive cases results in 323 actual cases of Down syndrome detected per 100,000 noninvasive prenatal screenings. This means that there is a 0.323 percent chance of a pregnancy that received a noninvasive prenatal test testing positive for Down syndrome and actually having Down syndrome.

Of the 4.09 million pregnancies that reach the end of the first trimester and are screened, we can then estimate that there will be 9,509 babies who are confirmed to have Down syndrome at the end of the first trimester. Approximately [67 percent](#) or 6,371 of those babies confirmed to have Down syndrome will be aborted.⁴¹ Absent abortion, an estimated [75 percent](#) would have survived to birth, representing 4,778 babies.⁴² Thus, an additional 4,778 babies with Down syndrome would have been born in 2019 if there was no selective abortion, representing an 80 percent increase over the current birth rate. Table 1 reports each step of this calculation.

Table 1. Calculation of Additional Babies Born with Down Syndrome Each Year Absent Selective Abortion, United States

Number of pregnancies annually:	6,369,000
Number of pregnancies adjusted for change in birth rate from 2009 to 2019:	5,744,688
Number of pregnancies each year adjusted for 1 st trimester miscarriages:	4,986,233
Number of pregnancies each year adjusted for 1 st trimester miscarriages and abortions:	4,088,711
Number of pregnancies screened:	2,943,872
Number of pregnancies screened that have Down syndrome:	9,509
Number of babies with Down syndrome who are aborted:	6,371*
Number of additional babies born each year absent selective abortion:	4,778**

Notes: *[Research suggests](#) that between 61-93 percent of pregnancies diagnosed with Down syndrome are terminated with a weighted mean termination rate of 67 percent.

**The average fetal loss rate for Down syndrome babies between the time of an amniocentesis diagnosis and birth is estimated to be [25 percent](#).

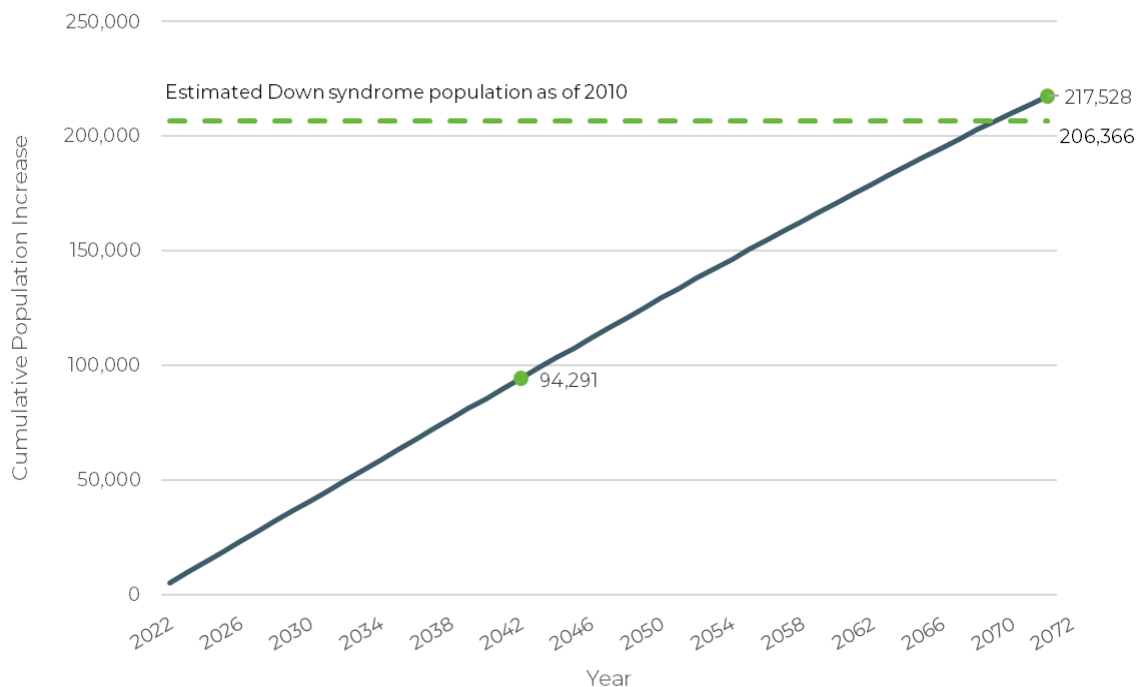
Using a different methodology—that takes as its starting point the number of babies born with Down syndrome each year rather than the number of total pregnancies—we validate our results in Appendix B by finding a similar result.

Population Estimate

We can also estimate how the population of people with Down syndrome in the United States would increase over time, absent selective abortion, using our estimate of 4,778 additional babies born with Down syndrome each year. Using [CDC](#) data on the number of deaths by age for Americans with Down syndrome in 2020 we calculate the probability of a person with Down syndrome dying at any given age.⁴³ These probabilities can be used to estimate the number of babies born who will be alive in a given year in the future.

Starting in 2022, we assume 4,778 additional babies with Down syndrome are born. In 2023, there are an additional 4,778 babies born plus the babies born in the 2022 cohort, minus any natural deaths.⁴⁴ The 2022 cohort's population in 2023 will be 4,778 times (1-probability of dying at age 0). The 2022 cohort's population in 2024 will be 4,778 times (1-probability of dying at age 0-probability of dying at age 1). This process can be repeated for each year and each cohort to estimate the additional number of people with Down syndrome who would be alive absent selective abortion over the next 50 years. Figure 4 displays the results.

Figure 4. Cumulative Down Syndrome Population Increase Absent Selective Abortion, United States, 2022-2072



Source: JEC Calculations; [CDC Wonder](#) Multiple Cause of Death data; Current population estimate from de Graaf, Gert, Frank Buckley, and Brian G. Skotko. "Estimation of the Number of People with Down Syndrome in the United States."

Figure 4 highlights the large impact of selective abortion on the Down syndrome

population. The figure shows that in 20 years there would be around 94,000 additional people with Down syndrome living in the United States if there was no selective abortion and around 218,000 additional people with Down syndrome after 50 years. These values are large relative to estimates from [recent studies](#) that find only around 206,000 people with Down syndrome in the United States as of 2010.⁴⁵ In other words, ending selective abortion would increase the population of Americans with Down syndrome in 50 years by more than the existing population of Americans with Down syndrome today. If selective abortion continues to rise, its impact would be even larger than the estimates shown in Figure 4.

CONCLUSION

Each person with Down syndrome is intrinsically and immeasurably valuable. In addition to reporting near universal levels of personal life satisfaction, Americans with Down syndrome are able to create widespread benefits for society. They have deep personal relationships, go to college, and [have children](#).⁴⁶ With appropriate support, they help our communities flourish. Selective abortion bolstered by a rise in prenatal testing robs society of the value that comes from people with Down syndrome. In a broader sense, genetic testing that leads to selective abortion affects more than just people with Down syndrome. It impacts anyone with any genetic anomalies who may wrongly be perceived as being less valuable than people without disabilities.

Given the ongoing legal challenges to *Roe v. Wade* and the potential for future changes to the legal status of abortion in some states, it is more important than ever to understand the value that people with Down syndrome bring not only for themselves but for their families and communities.

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Joint Economic Committee

APPENDIX

Appendix A. Study Comparison

Appendix Table 1. Comparisons between JEC Republican results for mean and median age of death of people with Down syndrome from 1999-2007 and results from Presson et al. (2013)

Year	Presson et al.		JEC Calculations	
	Mean	Median	Mean	Median
1999	43	50	42	49
2000	43	50	42	50
2001	43	51	42	51
2002	43	51	42	50
2003	45	52	44	51
2004	49	54	48	54
2005	46	53	45	52
2006	46	53	45	53
2007	47	53	47	53

Results from Presson et al. (2013) were derived from CDC registry of death certificate data ([Multiple Mortality Files](#)). JEC calculations were derived using [CDC Wonder](#) Multiple Cause of Death data where Down syndrome was listed as the primary or contributing cause of death. The results from the JEC calculations and the Presson et al. study are very similar as they are both drawn from the national registry of death data. Differences are likely due to the fact that Presson et al. adjusted for changes in International Classification of Diseases code classification over time.

Appendix B. Alternative Birth Calculation

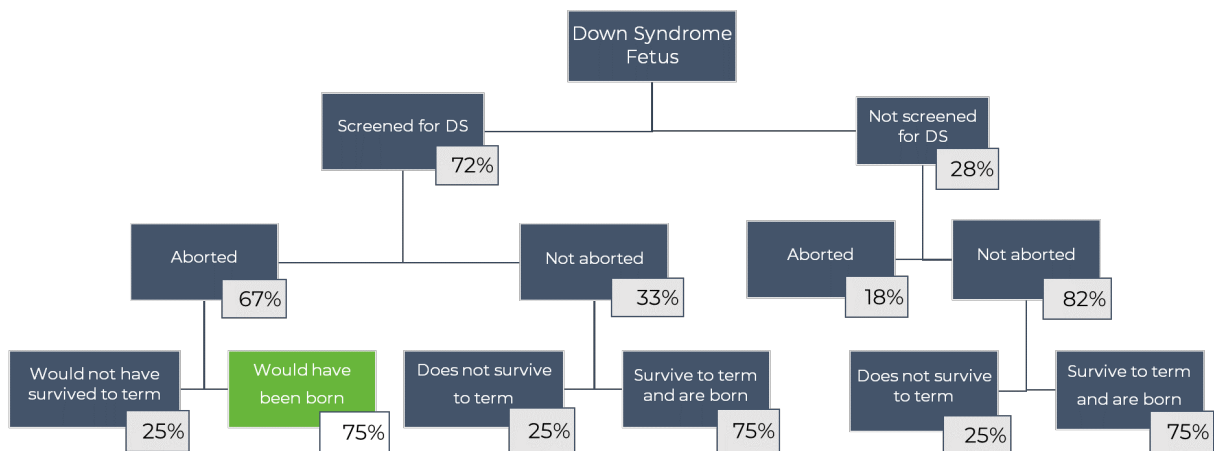
An alternative approach for estimating the number of additional births of babies with Down syndrome by ending selective abortion begins with the estimated [6,000 babies](#) with Down syndrome who are born each year. The number of babies with Down syndrome born is equal to the number of fetuses who actually have Down syndrome at the end of the first trimester times the probability of either (i) being screened for Down syndrome (0.72), not being aborted (0.33) and surviving to birth (0.75); or (ii) not being screened for Down syndrome (0.28) and surviving to birth (0.75). Using figures from the first birth estimate calculation, the probability of (i) is $0.18 = 0.72 \times 0.33 \times 0.75$, and the probability of (ii) is $0.21 = 0.28 \times$

0.75. Thus, a baby who has Down syndrome at the end of the first trimester has a 0.39 probability (0.18 + 0.21) of being born. This implies 15,456 fetuses with Down syndrome at the end of the first trimester (6,000 divided by 0.39).

The additional babies with Down syndrome who would be born absent selective abortion is the 15,456 babies with Down syndrome at the end of the first trimester, times the 72 percent who are currently screened, times the 67 percent of those screened who are currently aborted, times the 75 percent who would have survived to birth, for a total of 5,592 babies.

This estimate is close to the 4,778 babies found in the previous calculation and because the two calculations use two different starting points, they help validate one another. Appendix Figure 1 displays this calculation graphically.

Appendix Figure 1. Calculation of Additional Babies Born with Down Syndrome Each Year Absent Selective Abortion: Alternative Approach



One assumption of both the main and alternative estimates is that the natural loss rate and abortion rate are independent of each other. However, it may be the case that people have abortions because their baby is less likely to survive to term. In this case, the natural loss rate for the babies who are aborted would be higher than 25 percent and the natural loss rate for babies who are not aborted would be lower than 25 percent. If this is the case, then it is likely that the actual number of babies that would have been born would be slightly less than the 4,778 to 5,592 range we estimate. For this reason, we rely on the smaller 4,778 value for our population estimates.

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