

# People living with Down syndrome in the USA: BIRTHS AND POPULATION

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This fact sheet summarizes recently published estimates of the numbers of babies born and people living with Down syndrome in the USA.<sup>[1,2]</sup>

## Births

- **How many babies are born with Down syndrome each year?** As of 2010, we estimate that 1 in every 792 liveborn babies has Down syndrome (12.6 per 10,000). This means that there were about 5,300 babies with Down syndrome born annually in the U.S. in recent years. (Figure 1)

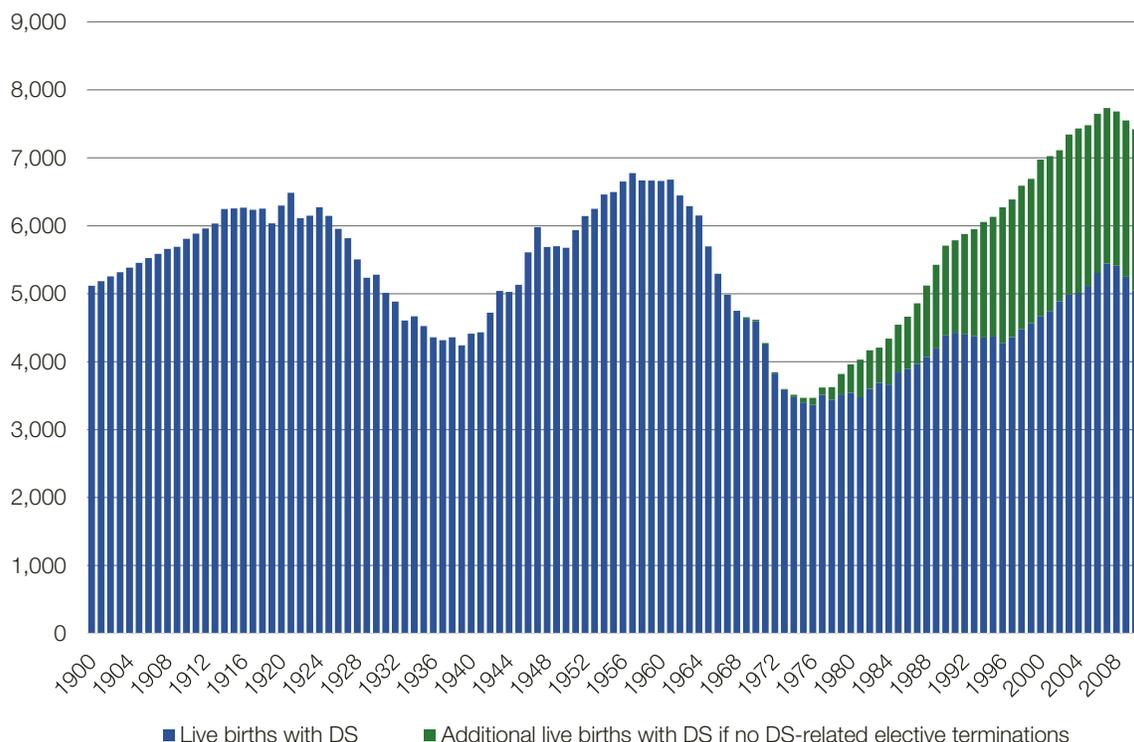


Figure 1. Births of babies with Down syndrome in the USA, 1900-2010

- **Are more pregnancies with Down syndrome being terminated than in the past?** In the few decades since prenatal screening was introduced, more pregnancies with Down syndrome have been diagnosed prenatally and terminated. However, not all children born with Down syndrome are diagnosed prenatally, and many expectant parents do not choose screening. Therefore, reductions

in live birth rates are influenced by the number of people choosing prenatal testing, the accuracy of the screening tests, and parents' decisions given a prenatal diagnosis. Approximately, 3,100 Down syndrome-related elective pregnancy terminations were performed annually in the U.S. in recent years.

- Are most pregnancies with Down syndrome now terminated?** Previous studies have suggested that around 74% of expectant parents in the U.S. who learn of a Down syndrome diagnosis prenatally choose to terminate.<sup>[3]</sup> However, many expectant couples choose not to pursue prenatal screening or diagnostic testing. Therefore, the 74% termination rate does not imply that 74% fewer babies were born; instead, it only reflects the decisions of couples who have already opted into screening. Actually, in the U.S., as a result of elective terminations, we estimate there was a 30% reduction in the numbers of babies with Down syndrome born in 2006-2010. This means that in recent years there were 30% fewer babies with Down syndrome than could have been born, absent elective terminations (Figure 1, green bars).
- What has happened to the overall birth rate?** Since the early 1980s, the effect of increasing maternal age has slightly outweighed the growth of prenatal screening followed by elective terminations, leading to an increase in the live birth prevalence of Down syndrome in the USA in recent decades - rising from around 10.1 per 10,000 livebirths (1 in 990) in the 1980s to around 12.3 per 10,000 livebirths in the 2000s (1 in 813). (Figure 2)

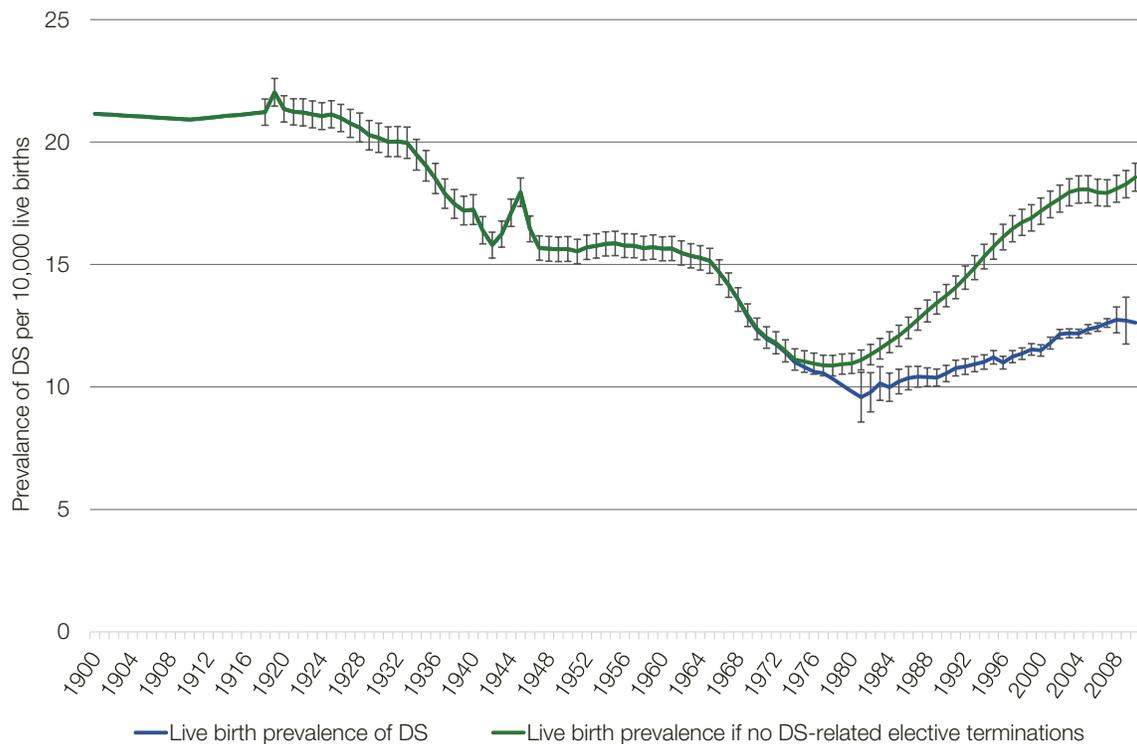


Figure 2. Live birth prevalence of Down syndrome in the USA, 1900-2010

- Are similar numbers of babies with Down syndrome born in all regions and all communities?** Previous research suggests that Down syndrome naturally occurs in all races and ethnicities, and that only maternal age differences influence the number of births. Our research adds that there are cultural differences between regions of the US in regards to Down syndrome-related

terminations. As of 2007, the reduction in babies born with Down syndrome was highest in the Northeast region and Hawaii. They were lowest in the South. There also appears to be racial/ethnic differences. From 2005-2009, the reduction of babies born with Down syndrome was highest among Asians/Pacific Islanders followed by non-Hispanic whites. The reduction was lowest among Hispanics and American Indians. However, higher reduction percentages tend to co-occur with higher maternal ages (and therefore with more pregnancies with a child with Down syndrome). As a result, the actual differences between regions and between ethnic groups in live birth prevalence are relatively small.

- How are newer non-invasive screening technologies influencing birth rates?** Our calculations **do not** capture the changes since noninvasive prenatal screens (NIPS) were introduced in 2011. Our calculations will provide a baseline to assess the impact of NIPS as more data becomes available in the coming years. We anticipate that it will not be until 2017 that we will have an opportunity to assess the impact of NIPS on its first full year of use in 2012.

## Population

- How many people with Down syndrome are living in the U.S. today?** Including people born outside of the U.S., we estimate that the number of people with Down syndrome living in the U.S. has grown from 49,923 in 1950 to 206,366 in 2010 (Figure 3).
- What proportion of the U.S. population are people with Down syndrome?** The population prevalence of Down syndrome, as of 2010, is estimated at 6.7 per 10,000 inhabitants (or 1 in 1,499).

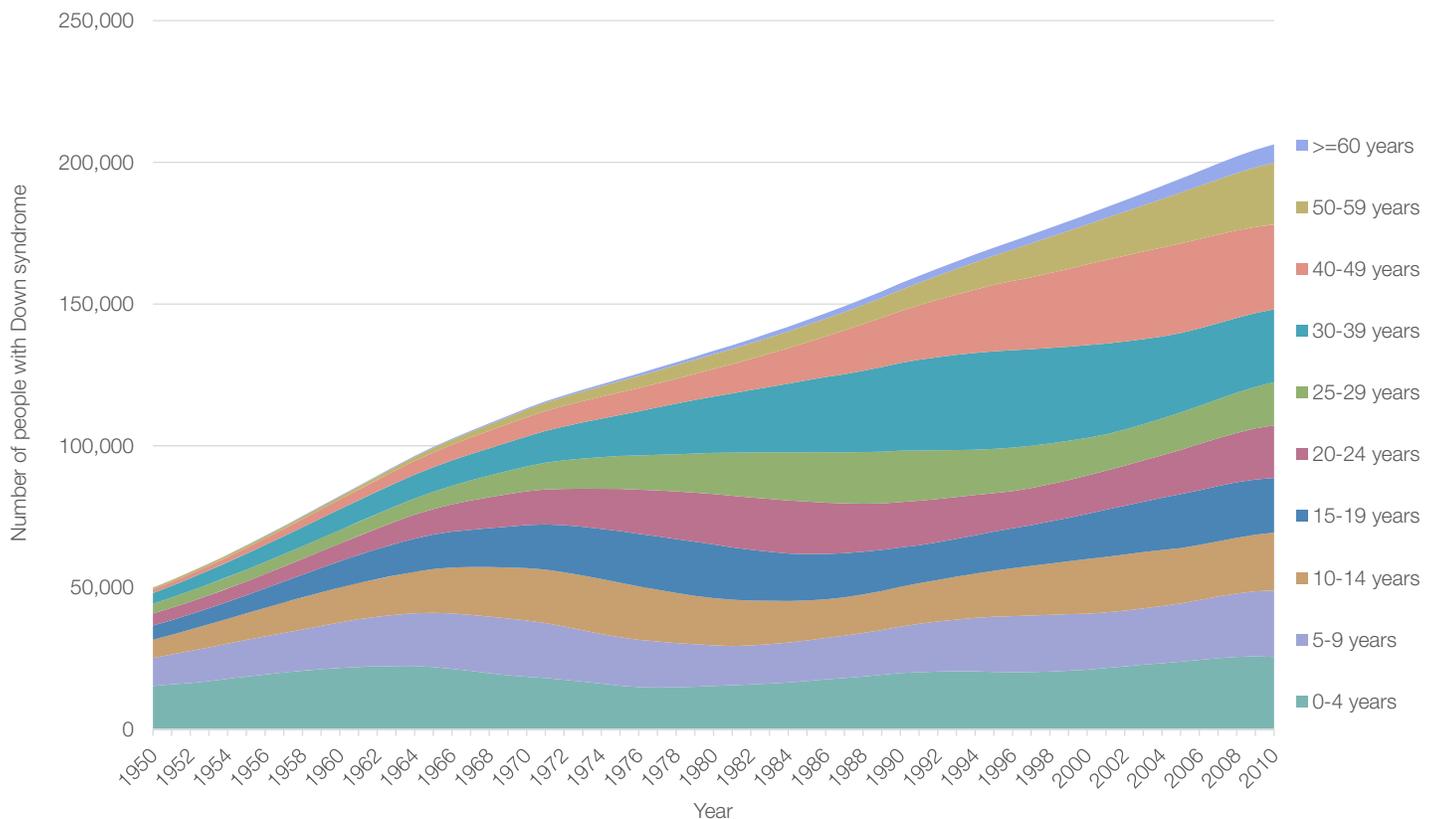


Figure 3. Population of people with Down syndrome in the USA, 1950-2010

- **Is Down syndrome a “rare disease”?** Our estimates indicate that until 2008, Down syndrome was a rare disease, typically defined in the U.S. as a population of fewer than 200,000 persons.
- **What is the ethnic composition of today’s population of people with Down syndrome?** We estimated the population of people with Down syndrome living in the U.S. in 2010 to include 138,019 non-Hispanic whites, 27,141 non-Hispanic blacks, 32,933 Hispanics, 6,747 Asians/Pacific Islanders, and 1,527 American Indians/American Natives.
- **Are the populations of people with Down syndrome growing at similar rates in all ethnic groups?** In more recent decades, the population growth of people with Down syndrome has leveled off for non-Hispanic whites, a consequence of elective terminations. The growth in the population of people with Down syndrome is strongest in the more recent immigration groups, Asians/Pacific Islanders and Hispanics. This is a result of these ethnic groups consisting of relatively many young people starting families and having children.
- **How has life expectancy changed for people with Down syndrome?** There has been a rising mean and median life expectancy, growing from an estimated 26 years (mean) and 4 year (median) in 1950 to 53 years (mean) and 58 years (median) in 2010.<sup>a</sup>

## Notes

- a. Importantly, there is a difference between “life expectancy” and “mean age of death”. “Life expectancy” is a prediction of how many years a person born in a specific year of birth probably will live, whereas “mean age of death” tells us what is the average age of death in the calendar year under observation. Mean age of death is strongly influenced by the age distribution of people living in the specific population, which is a result of the relative sizes of birth cohorts and of historical childhood survival rates within these cohorts. According to our model, mean and median age of death increased, too, and even more rapidly from respectively an estimated 3 years (mean) and 0 years (median) in 1950, 12 years (mean) and 2 years (median) in 1970, 35 years (mean) and 38 years (median) in 1990, to 48 (mean) years and 54 years (median) in 2010. There are some small differences in life expectancy for people with Down syndrome between ethnic groups. However, there are pronounced differences between ethnic groups in age of death. In particular, more recent immigrant groups have lower ages of death, not because of less favorable survival rates, but because these groups include relatively more children and fewer older people.

## References

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3. Natoli, J. L., Ackerman, D. L., McDermott, S. and Edwards, J. G. (2012), Prenatal diagnosis of Down syndrome: a systematic review of termination rates (1995–2011). *Prenatal Diagnosis*, 32: 142–153. doi:10.1002/pd.2910 [<http://dx.doi.org/10.1002/pd.2910>]