

Study estimates number of births, population prevalence of Down syndrome in nine states

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A new study estimates, for the first time, both the numbers of children born annually with Down syndrome in nine U.S. states and the prevalence of Down syndrome in each of those states' populations. Published in the *American Journal of Medical Genetics, Part A*, the study is a follow up to the same team's previous investigations of how the numbers of people with Down syndrome in the U.S. changed over a period of 60 years and the number of births and pregnancy terminations with Down syndrome in Massachusetts since the beginning of the 20th century.

"The numbers of people with Down [syndrome](#) living in a state is influenced both by the numbers of babies born each year and by the expanding lifespan of people with Down syndrome," explains Brian Skotko, MD, MPP, of MassGeneral Hospital for Children, co-director of the Massachusetts General Hospital Down Syndrome Program and senior author of the study. "People with Down syndrome are living longer than ever before, but the increased use of prenatal testing for this and other genetic diseases has had a counterbalancing effect, leading to a plateauing of total numbers in many states."

The states represented in this study - Massachusetts, New Jersey, New York, Illinois, Indiana, Michigan, Florida, Kentucky and Arizona—were chosen based on the availability of data on numbers of children born with Down syndrome over several years. Numbers of elective terminations were calculated based on the difference between actual births and what would be expected based on numbers of older

mothers—who are both at a greater chance of pregnancies with Down syndrome and more likely to have prenatal screening.

In 2010, there was an estimated total of 1,386 annual births with Down syndrome across the nine states, corresponding to 1 in 824 live births. Live [birth](#) prevalence ranged from 1 in 729 in Florida to 1 in 1,256 in Kentucky. The estimated reduction percentage - the proportion of live births reduced as a result of elective termination - was 39 percent overall and ranged from 26 percent in Indiana and Michigan to 52 percent in New Jersey. The researchers estimate that without terminations, an additional 898 individuals with Down syndrome would have been born in the nine states during 2010.

The effects of elective termination on the population size of people with Down syndrome, which was estimated to produce an overall drop of 22 percent in individuals with Down syndrome living in these states, ranged from a 11 percent reduction in Kentucky to 30 percent in Massachusetts. Among different ethnic groups, population size reduction was highest at 51 percent in Asian/Pacific Islanders, followed by 22 percent in non-Hispanic whites, 21 percent in non-Hispanic blacks, 17 percent among Hispanics and 4 percent among Native Americans/Alaskans.

While elective termination has reduced the prevalence of Down syndrome in all nine states, the researchers note that total numbers of people living with Down syndrome steadily increased from 1950 to 2010, the last year for which data was available. The higher level of termination in the Northeast—specifically Massachusetts, New York and New Jersey - is probably attributable to numbers of older mothers and increased willingness to terminate a pregnancy because of Down syndrome.

"Statewide organizations need to know whether they are reaching all of the families in their communities who could benefit from their services,"

explains Skotko, who is an assistant professor of Pediatrics at Harvard Medical School. "With our new results, they will be able to know what percentage of newborns they are reaching, and with our total population data they will be able to determine what percentage of the total estimated numbers of people with Down syndrome their membership represents, by age, race and ethnicity. Such data can help organizations identify gaps in their services and provide information to help them track the efficacy of changes in their outreach and recruitment efforts."

Skotko notes that data on years after 2010, which is becoming available, will help measure the impact of the new, noninvasive screening method that was introduced in 2011. A nationwide database or registry of births with Down syndrome, including the more comprehensive data that was available for the nine states in this study but not the other 41 states, would be very helpful in expanding this study's results to the whole country.

More information: Gert de Graaf et al, Estimation of live birth and population prevalence of Down syndrome in nine U.S. states, *American Journal of Medical Genetics Part A* (2017). [DOI: 10.1002/ajmg.a.38402](https://doi.org/10.1002/ajmg.a.38402)

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