

# People living with Down syndrome in New Zealand: 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 New Zealand.<sup>[1]</sup>**

## Births

- **How many babies are born with Down syndrome each year in New Zealand?** For the period of 2016–2020, we estimate there were 41 live births of children with Down syndrome per year. This equates to a rate of around 1 in every 1,450 live births across New Zealand (6.9 per 10,000 live births; Figure 1).<sup>[a]</sup>
- **What has happened to the birth rate over time in New Zealand?** Since the 1970s, the introduction and growth of prenatal screening and elective terminations have resulted in a live birth prevalence at around 6.9 per 10,000 live births. The expected live birth prevalence, absent elective terminations, has steadily increased since the 1980s (Figure 1). In the absence of prenatal screening and elective terminations, live birth rates for babies with Down syndrome in New Zealand today would be more than three times as high as the current levels.

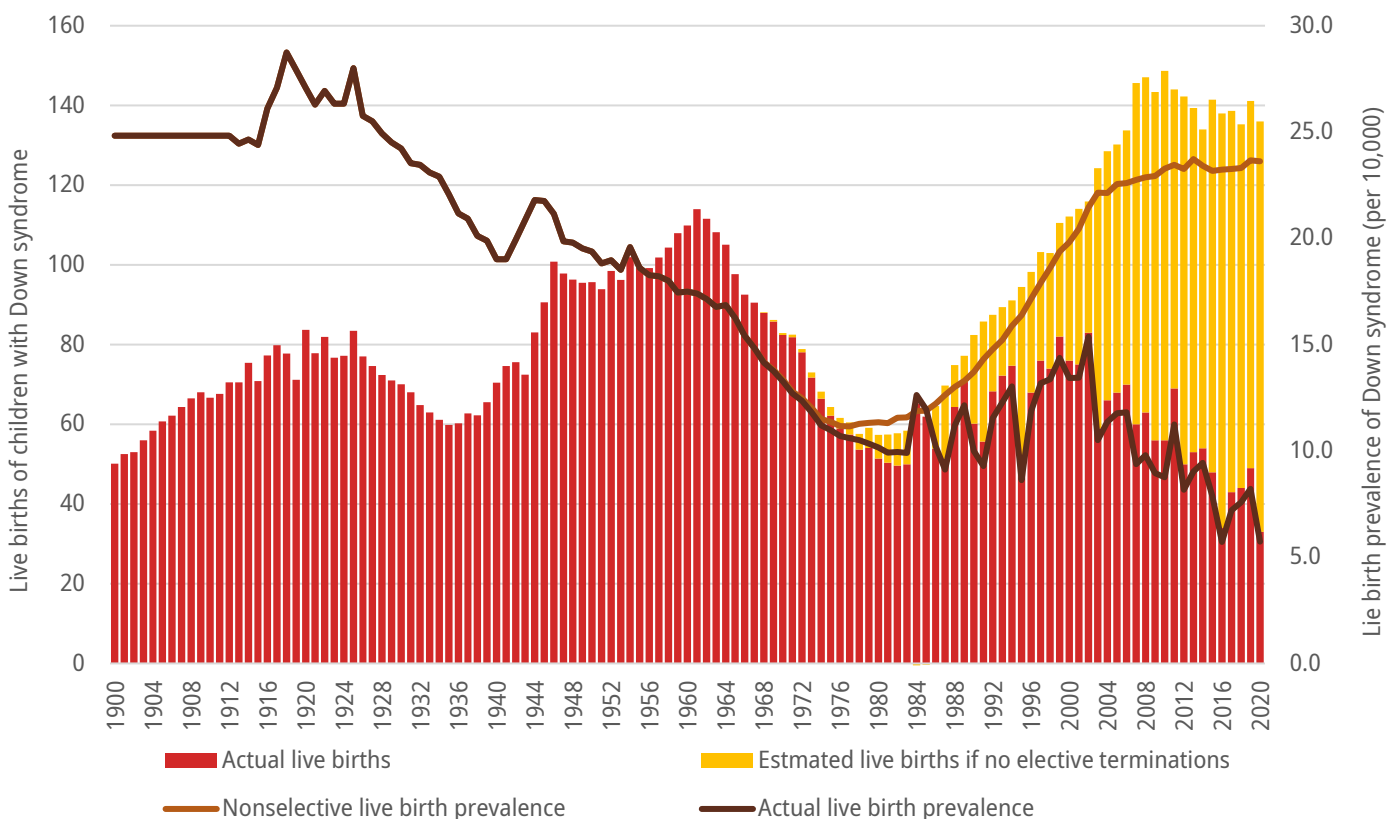


Figure 1. Births of babies with Down syndrome and live birth prevalence in New Zealand, 1900–2020.

- **Are more pregnancies with Down syndrome being terminated in New Zealand than in the past?** In the 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. The percentage of live births of babies with Down syndrome reduced as a result of screening and terminations has risen in New Zealand over the past 40 years to 71% today. Put another way, this means that in recent years there were 71% fewer babies with Down syndrome than could have been born in New Zealand, if not for elective termination (Figure 2).



Figure 2. The percentage of live births of babies with Down syndrome reduced as a result of screening and elective terminations in New Zealand, 1965–2020 (5-year running averages).

- **Does New Zealand have a higher rate of selective termination of pregnancies with Down syndrome compared to other countries?** As of 2016–2020, the reduction percentage was 71% in New Zealand (NZ) and 66% in Australia. The most recent data for the United States (U.S.) and Europe are for the period 2011–2015. For these years, the reduction percentage was estimated at 61% for New Zealand, 64% for Australia, 62% for Europe (excluding the former East bloc), and only 32% for the U.S. However, both within Europe and the U.S., there is a wide variation. For instance in Europe, excluding former East bloc countries and countries with a very restrictive abortion policy (Malta and Ireland), the reduction rate ranged from 40% in Sweden to 84% in Spain.
- **How are newer non-invasive screening technologies influencing birth rates?** Our study does not suggest that the introduction of noninvasive prenatal screening (NIPS) in New Zealand has had an impact on birth rates. However, the effect of NIPS on birth rates may increase if public funding would become available.

# Population

- **How many people with Down syndrome are living in New Zealand today?** We estimate that the number of people with Down syndrome living in New Zealand has grown from 742 in 1950 to 3,065 people with Down syndrome as of 2020 (Figure 3).<sup>[b]</sup>

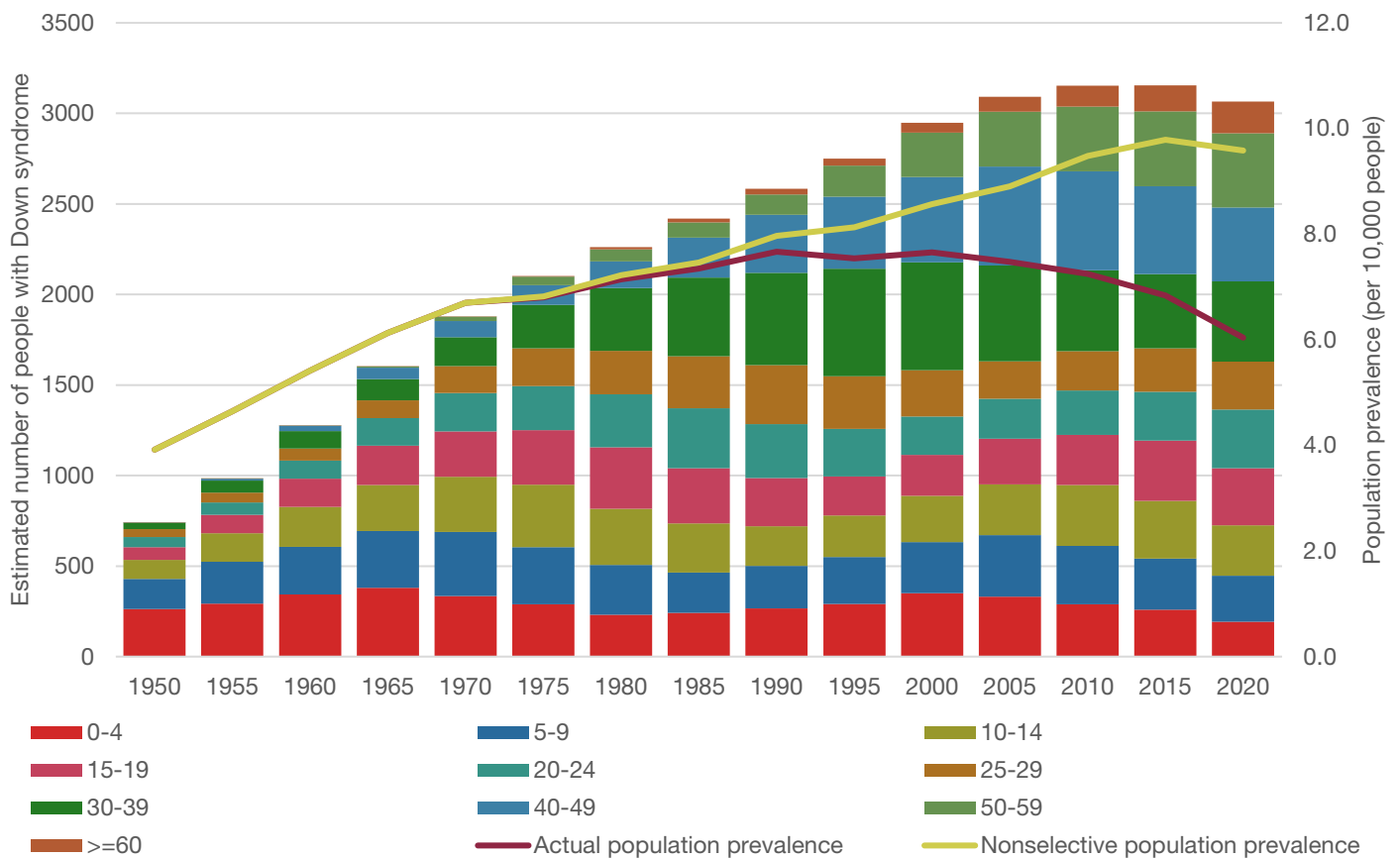


Figure 3. The number of people living with Down syndrome in New Zealand, 1950–2020.

- **How do selective terminations impact on the population of people with Down syndrome in New Zealand?** We estimate that there would be 4,862 people with Down syndrome living in New Zealand today if there had been no elective terminations.
- **What proportion of the New Zealand population are people with Down syndrome?** The population prevalence of Down syndrome in New Zealand, as of 2020, is estimated at 6.0 per 10,000 inhabitants (or 1 in 1,655; Figure 3).
- **How has life expectancy changed for people with Down syndrome?** In high income countries, including New Zealand, there has been an increase in life expectancy since 1950. Our modeling for New Zealand suggests a median life expectancy of around 7 years of age in 1950, increasing steeply to around 53 years of age in 1970, followed by a gradual rise to 58 years of age from 2000 onwards.<sup>[b]</sup>
- **How has the age distribution of the population of people with Down syndrome changed?** Improvements in life expectancy has changed the age distribution of people with Down syndrome. In 1950, 81% of people with Down syndrome living in New Zealand were under the age of 20, and less than 1% were 40 years and older. In 2020, 34% of people with Down syndrome were under the age of 20 and 32% were aged 40 years and older. Nowadays, in New Zealand and other high income countries, there are many persons with Down syndrome in their fourth, fifth, and sixth decades of life.

# Notes

- a. There is some uncertainty in the estimates of LB prevalence due to incompleteness of data. Sources and uncertainties are detailed in the supplementary information available with our paper.<sup>[1]</sup>
- b. We have assumed that a lower 1-year survival in the general population will be indicative for a less well-developed medical care system, which will concomitantly impact the survival of children with DS. For the U.S, the different European countries, NZ, and Australia, we constructed country-specific survival curves by year of birth for people with DS on the basis of their historical and current 1-year mortality rates in the general population. We compared the model projections with population counts of people with DS, if available, and with data on the distribution of age at death of people with DS from national statistics. For the U.S., the different European countries (excluding former East bloc countries), NZ, and Australia, the projections matched the empirical data. Further details are available in our papers and supplementary materials.<sup>[1-4]</sup>

# References

1. de Graaf G., Skladzien E., Buckley F., Skotko B. G. (2022). Estimation of the number of people with Down syndrome in Australia and New Zealand. *Genetics in Medicine*. Published online: October 03, 2022. [doi:10.1016/j.gim.2022.08.029](https://doi.org/10.1016/j.gim.2022.08.029)
2. de Graaf G., Buckley F., Skotko B. G. (2017). Estimation of the number of people with Down syndrome in the United States. *Genetics in Medicine*, 19(4), 439-447. [doi:10.1038/gim.2016.127](https://doi.org/10.1038/gim.2016.127)
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# Other population factsheets available

Australia: <https://go.downsyndromepopulation.org/australia-factsheet>

US: <https://go.downsyndromepopulation.org/usa-factsheet>

Europe: <https://go.downsyndromepopulation.org/europe-factsheet>