People living with Down syndrome in Australia: 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 Australia.[1]

Births

- **How many babies are born with Down syndrome each year in Australia?** For the period of 2016–2020, we estimate there were 265 live births of children with Down syndrome per year. This equates to a rate of around 1 in every 1,158 live births across Australia (8.6 per 10,000 live births; Figure 1).[a]
- **What has happened to the birth rate over time in Australia?** Since the 1970s, the introduction and growth of prenatal screening and elective terminations have resulted in a live birth prevalence at around 8.6 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 Australia today would be almost three times as high as the current levels.

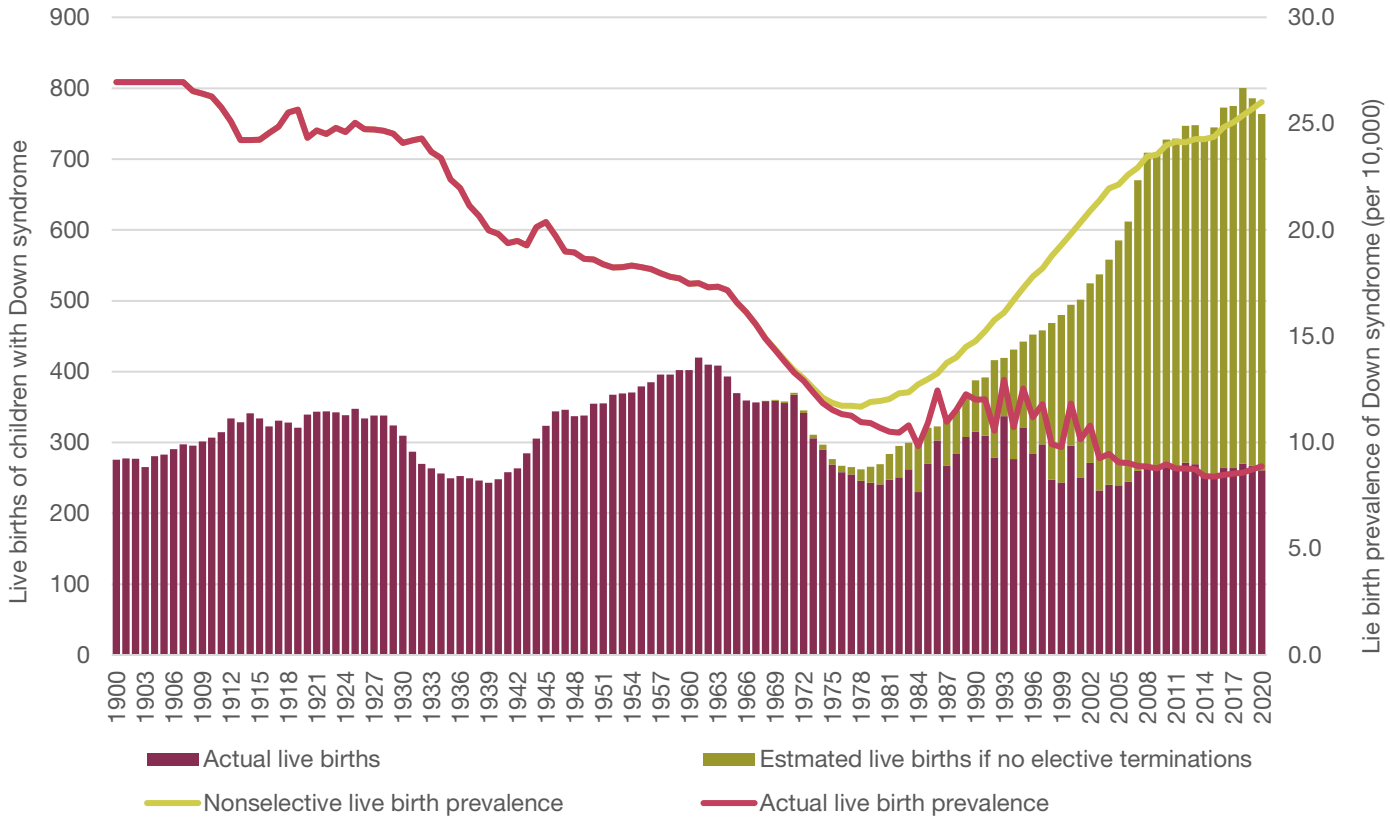

Figure 1. Births of babies with Down syndrome and live birth prevalence in Australia, 1900–2020.

- **Are more pregnancies with Down syndrome being terminated in Australia 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 Australia over the past 40 years to 66% today. Put another way, this means that in recent years there were 66% fewer babies with Down syndrome than could have been born in Australia, if not for elective termination (see Figure 2).

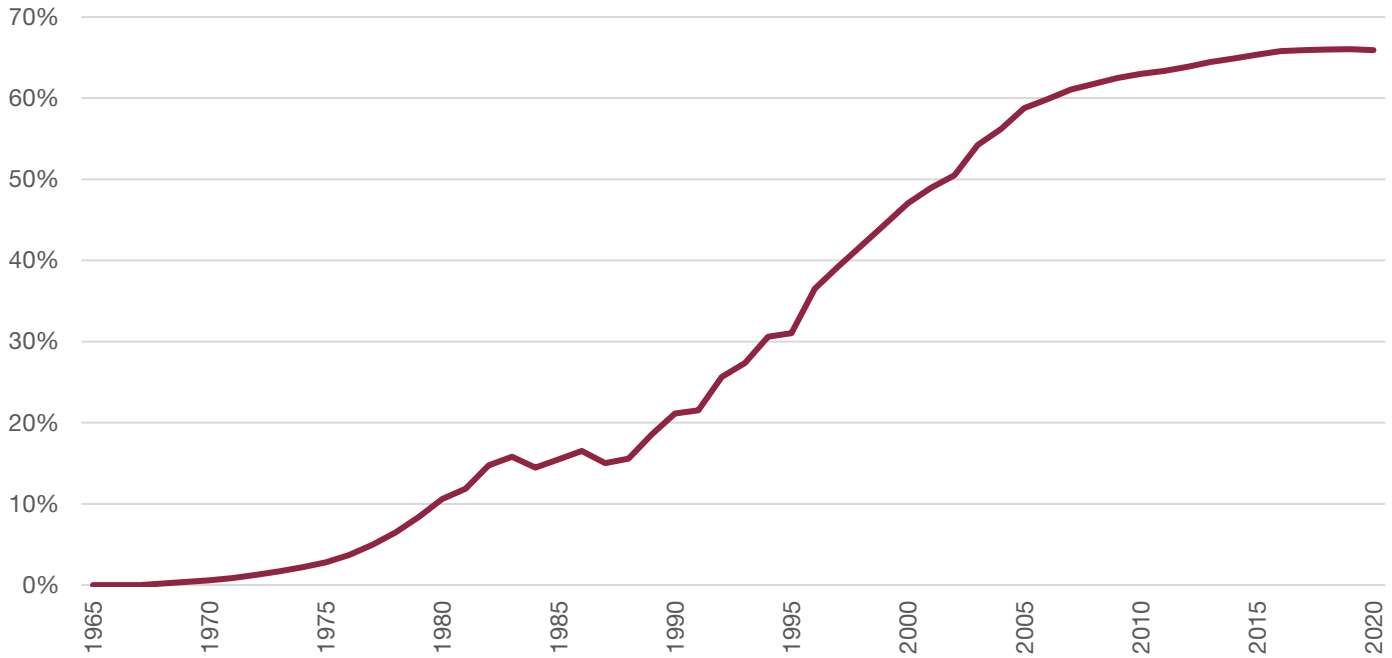

Figure 2. The percentage of live births of babies with Down syndrome reduced as a result of screening and elective terminations in Australia, 1965–2020 (5-year running averages).

- **Does Australia have a higher rate of selective termination of pregnancies with Down syndrome compared to other countries?** As of 2016–2020, the reduction percentage was 66% in Australia and 71% in New Zealand (NZ). 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 64% for Australia, 61% for NZ, 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.

- **Are there differences in the rates of selective termination of pregnancies between Australian states?** Within Australia, the reduction rate varied only modestly. For the most recent years with data available for every main state (2008–2011 combined with 2013–2014), the reduction rate varied between 58% in Queensland to 69% in South Australia (the Australian average was 63% in this time frame).

- **How are newer non-invasive screening technologies influencing birth rates?** Our study does not suggest that the introduction of noninvasive prenatal screening (NIPS) in Australia 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 Australia today?** We estimate that the number of people with Down syndrome living in Australia has grown from 2,852 in 1950 to 13,426 people with Down syndrome as of 2020 (Figure 3).[b]

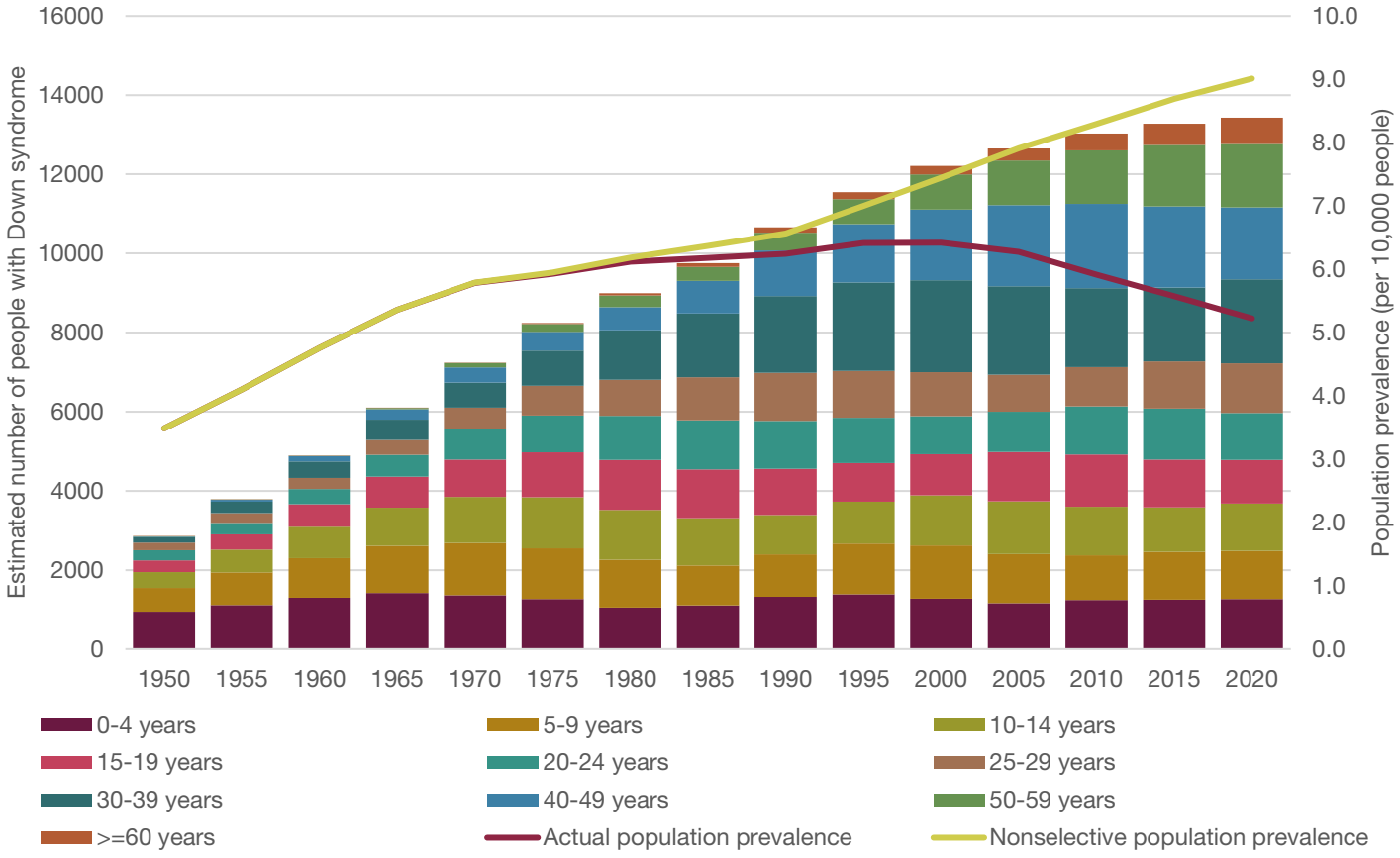

Figure 3. The number of people living with Down syndrome in Australia, 1950–2020.

- **How do selective terminations impact on the population of people with Down syndrome in Australia?** We estimate that there would be 23,156 people with Down syndrome living in Australia today if there had been no elective terminations.

- **What proportion of the Australian population are people with Down syndrome?** The population prevalence of Down syndrome in Australia, as of 2020, is estimated at 5.2 per 10,000 inhabitants (or 1 in 1,914; Figure 3).

- **How has life expectancy changed for people with Down syndrome?** In high income countries, including Australia, there has been an increase in life expectancy since 1950. Our modeling for Australia suggests a median life expectancy of around 8 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.[b]

- **How has the age distribution of the population of people with Down syndrome changed?** Improvement in life expectancy has changed the age distribution of people with Down syndrome. In 1950, 79% of people with Down syndrome living in Australia were under the age of 20, and less than 1% were 40 years and older. In 2020, 36% of people with Down syndrome were under the age of 20 and 30% were aged 40 years and older. Today, as in other high income countries, many people with Down syndrome are living into their 40s, 50s and 60s.

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.[1]

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 (for Australia, we could compare with data from the National Disability Insurance Agency), 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.[1-4]

References

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