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

Births

- **How many babies are born with Down syndrome each year in Canada?** For the period of 2016–2020, we estimate there were 431 live births of children with Down syndrome per year. This equates to a rate of around 1 in every 868 live births across Canada (11.5 per 10,000 live births; Figure 1).[a]
- **What has happened to the birth rate over time in Canada?** Since the 1970s, the introduction and growth of prenatal screening and elective terminations have resulted in a live birth prevalence at around 11.5 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 Canada today would be slightly more than two times as high as the current levels.

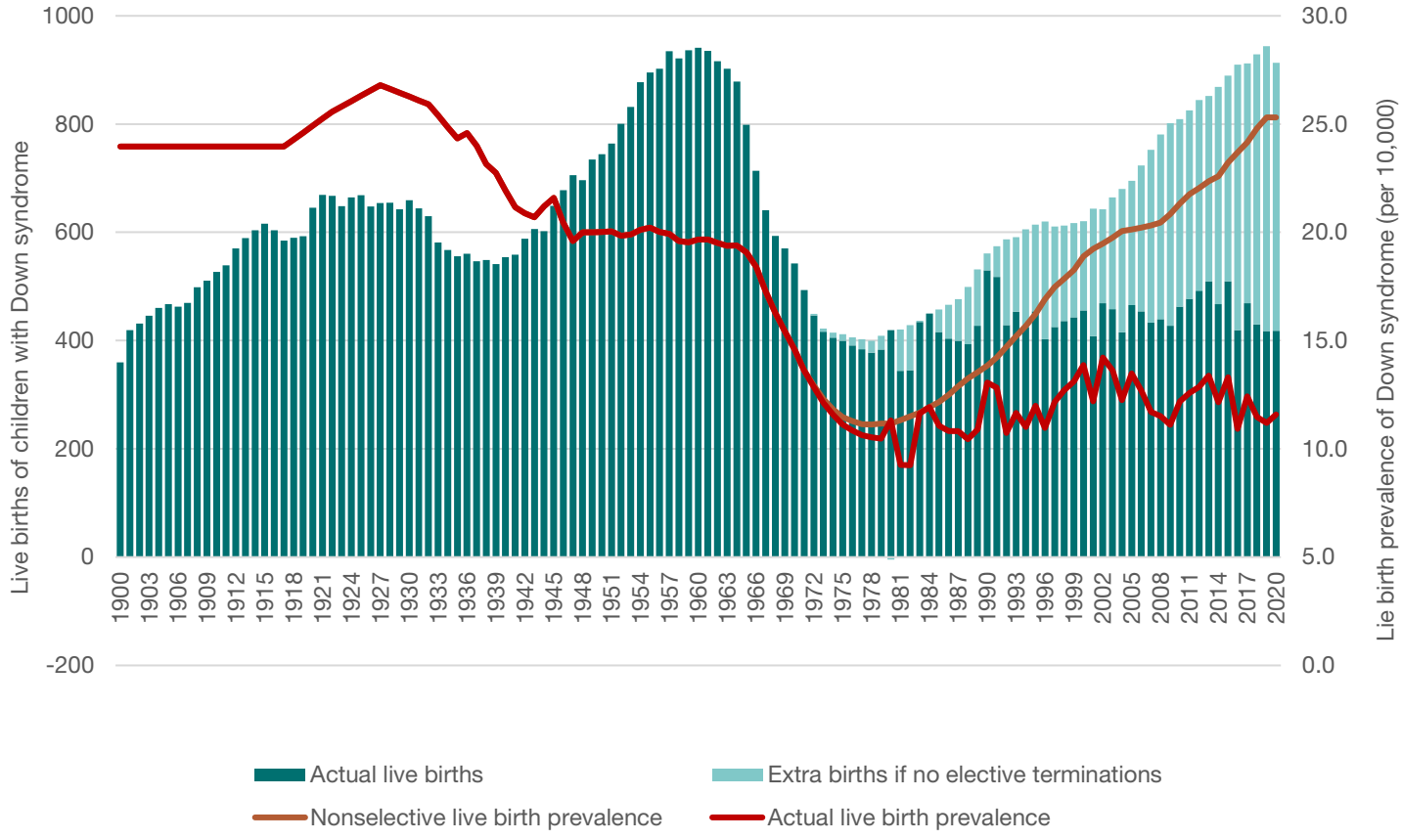

Figure 1. Births of babies with Down syndrome and live birth prevalence in Canada, 1900–2020.

- **Are more pregnancies with Down syndrome being terminated in Canada 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 Canada over the past 40 years to 54% in 2020. Put another way, this means that in recent years there were 54% fewer babies with Down syndrome than could have been born in Canada, if not for elective termination (see Figure 2).

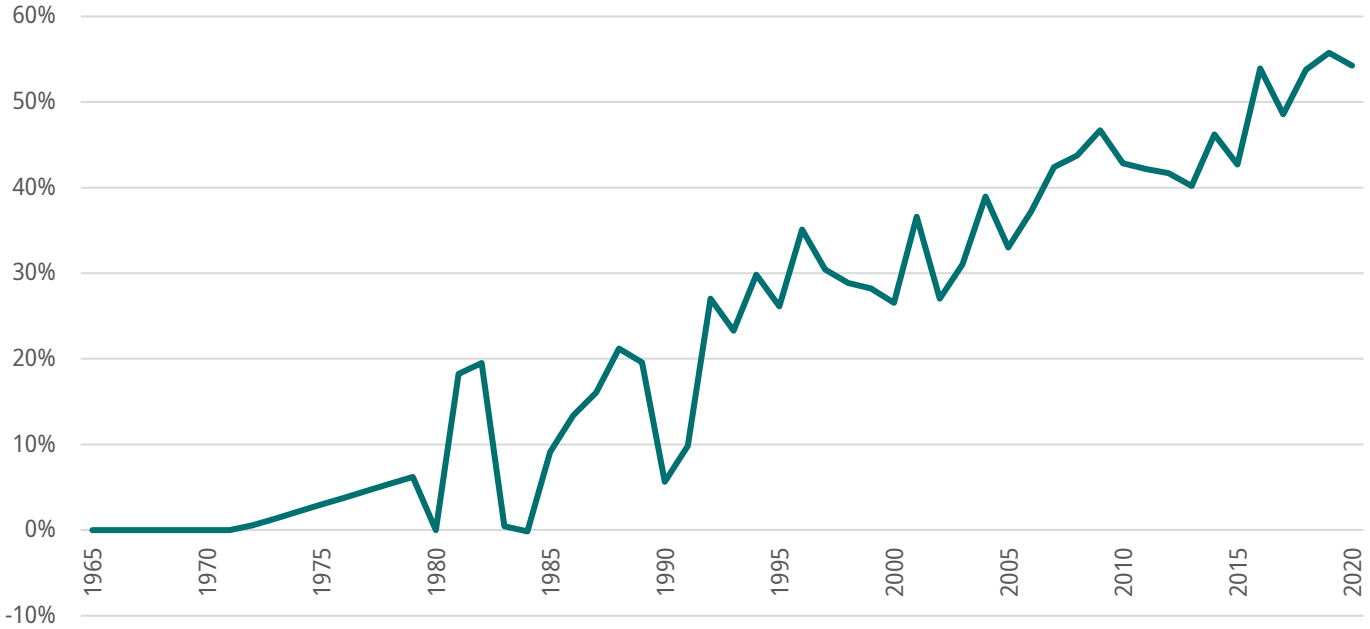

Figure 2. The percentage of live births of babies with Down syndrome reduced as a result of screening and elective terminations in Canada, 1965–2020 (5-year running averages).

- **Does Canada have a higher rate of selective termination of pregnancies with Down syndrome compared to other countries?** As of 2016–2020, the reduction percentage was 53% in Canada, 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 43% for Canada, 64% for Australia, 61% for NZ, 62% for Europe (excluding the former East bloc), and 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 screening technologies influencing birth rates?** This question is difficult to answer, as the reduction rate can vary over time regardless of the introduction of prenatal cell-free DNA testing, also known as noninvasive prenatal screening (NIPS). Between 2007 and 2015, the reduction rate in Canada remained relatively stable at just above 40%. Since 2016, this rate has risen to 53%. In 2013, NIPS was introduced in Canada. In 2014, some provinces began funding NIPS for pregnant women at increased risk of Down syndrome. Given the duration of pregnancies, any initial effects of this policy would be expected from 2015 onwards. The increase starting in 2016 may therefore be related to public funding for NIPS. The impact of NIPS on birth rates may become more pronounced if funding were extended to all pregnant women, rather than only higher-risk groups.

Population

- **How many people with Down syndrome are living in Canada today?** We estimate that the number of people with Down syndrome living in Canada has grown from 5,138 in 1950 to 22,367 people with Down syndrome as of 2020 (Figure 3).[b]

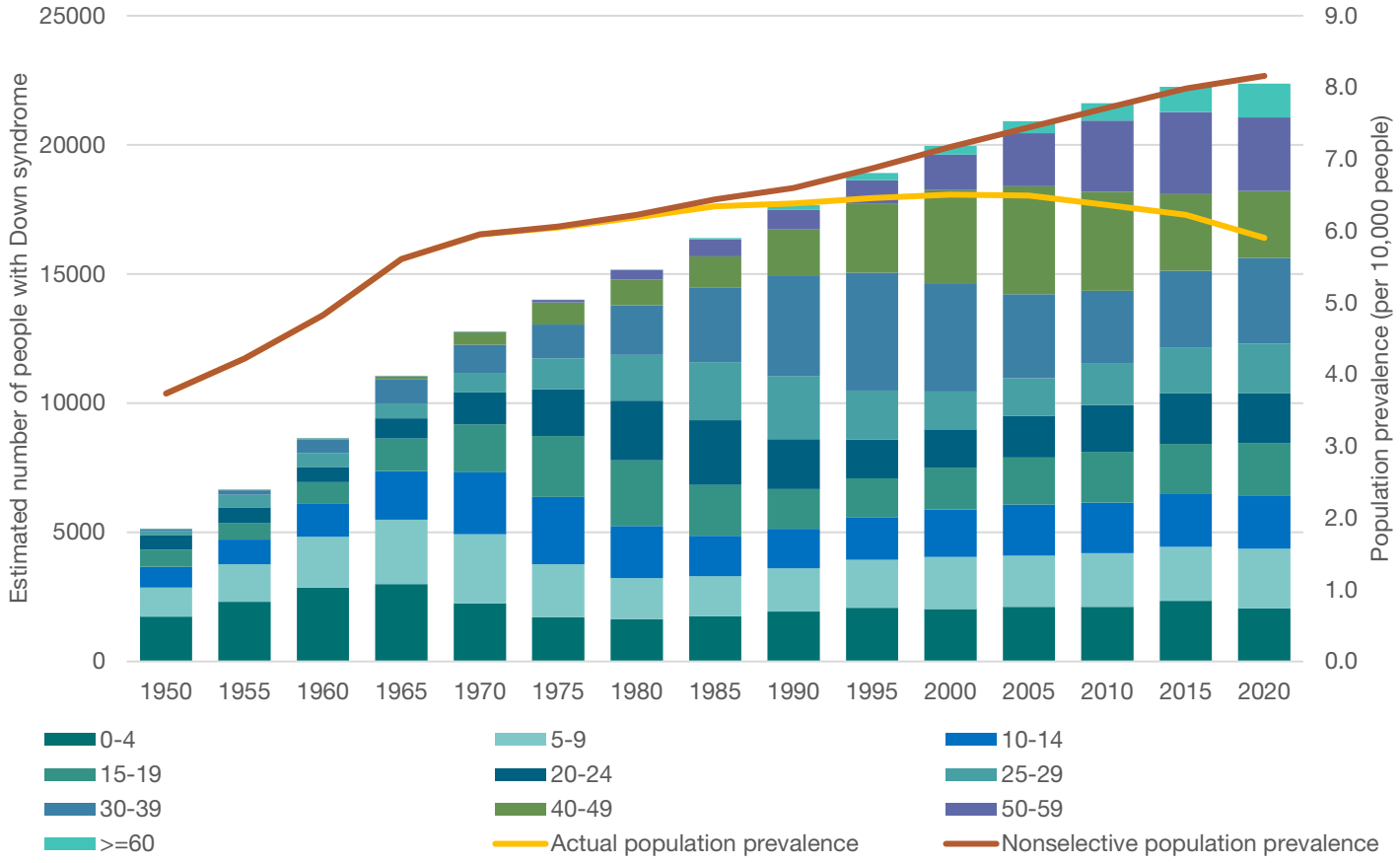

Figure 3. The number of people living with Down syndrome in Canada, 1950–2020.

- **How do selective terminations impact on the population of people with Down syndrome in Canada?** We estimate that there would be 30,922 people with Down syndrome living in Canada today if there had been no elective terminations.

- **What proportion of the Canadan population are people with Down syndrome?** The population prevalence of Down syndrome in Canada, as of 2020, is estimated at 5.9 per 10,000 inhabitants (or 1 in 1,694; Figure 3).

- **How has life expectancy changed for people with Down syndrome?** In high income countries, including Canada, there has been an increase in life expectancy since 1950. Our modeling for Canada suggests a median life expectancy of around 4 years of age in 1950, increasing steeply to around 53 years of age in 1970, followed by a gradual rise to 59 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, 84% of people with Down syndrome living in Canada were under the age of 20, and less than 1% were 40 years and older. In 2020, 38% 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 Canada, 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, Australia and Canada, the projections matched the empirical data. Further details are available in our papers and supplementary materials.[1-5]

References

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