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

Births

• **How many babies are born with Down syndrome each year in Europe?** For the period 2011–2015, we estimate 8,031 annual live births of children with Down syndrome – a rate of around 1 in every 990 live births across Europe (10.1 per 10,000 live births; Figure 1).

• **What has happened to the birth rate over time in Europe?** Since the 1970s, the introduction and growth of prenatal screening and elective terminations has resulted in a live birth prevalence at around 10 per 10,000 live births, while the expected non-selective live birth prevalence has steadily increased since the early 1980s (Figure 1). Across Europe, the birth rate has declined by 11.0% over the past 30 years, though there are considerable differences between different regions and different countries (Figure 2). In the absence of prenatal screening and elective terminations, live birth rates across Europe today would be more than double current levels.

Figure 1. Births of babies with Down syndrome and live birth prevalence in Europe, 1900–2015.
Figure 2. Changes in the nonselective and live birth prevalence of Down syndrome in European countries, between 1981–1985 and 2011-2015. * Termination of pregnancies were not permitted by law in Ireland and Malta during these periods. (US comparison based on previously reported modelling,[2-4] updated with recent data.)
• **Are more pregnancies with Down syndrome being terminated in Europe 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. The percentage of live births of babies with Down syndrome reduced as a result of screening and terminations has steadily risen in Europe over the past 40 years to over 50% today (Figure 3). Put another way, this means that in recent years there were 50% fewer babies with Down syndrome than could have been born in Europe, absent elective terminations.

![Figure 3. The percentage of live births of babies with Down syndrome reduced as a result of screening and elective terminations in Europe, 1965–2015.](image)

• **How are newer non-invasive screening technologies influencing birth rates?** Noninvasive prenatal screening (NIPS) has only recently been implemented in certain European countries. As data from these recent years are not yet available, our modeling does not yet provide an assessment of the impact of NIPS within Europe.

• **Are similar numbers of babies with Down syndrome born in all regions and all countries throughout Europe?** Differences in maternal ages, different laws, healthcare provisions, and cultural attitudes lead to differences in birth rates between different countries and regions. Among the four geographic European regions, between 2011 and 2015, live birth prevalence was lowest (8.3 per 10,000) in Southern Europe and highest in Northern Europe (11.4 per 10,000) with a reduction rate of 72% in Southern Europe and a reduction rate of 51% in Northern Europe (Figure 4). Within each region, there are substantial differences between individual countries (Figure 4).[a]
Figure 4. Live birth prevalence of people with Down syndrome per 10,000 live births in Europe, 2011–2015, and the effect of elective terminations. Percentages represent the reduction of Down syndrome prevalence as a consequence of selective terminations.
Population

• **How many people with Down syndrome are living in the Europe today?** On basis of our modelling,[a] we estimate that 419,000 people with Down syndrome were living in Europe as of 2015 (Figure 5).

![Figure 5. The number of people living with Down syndrome in Europe, 1950–2015.](image)

• **What proportion of the European population are people with Down syndrome?** The population prevalence of Down syndrome in Europe, as of 2015, is estimated at 5.7 per 10,000 inhabitants (or 1 in 1,767; Figure 6).

• **How has life expectancy changed for people with Down syndrome?** For European countries that were not formerly part of the East bloc, there has been a steep rise in median life expectancy between 1950 and 1970 from around 3 years in 1950 to around 53 years of age in 1970, followed by a gradual rise to 58 years of age, in more recent years. Our model suggests that for former East bloc countries, the rise in median life expectancy occurred later, for some countries only as of 1995. More recently, according to our modeling, the median life expectancy in these countries is also approaching 58 years of age.
### Figure 6. The prevalence of people living with Down syndrome in Europe, 2015.

Percentages reflect the reduction in the population prevalence of Down syndrome because of selective terminations.

![Population prevalence graph]

**Western Europe**
- Austria: 32%
- Belgium: 40%
- France: 41%
- Germany: 26%
- Luxembourg: 42%
- Netherlands: 20%
- Switzerland: 33%
- Total Western Europe: 28%

**Northern Europe**
- Denmark: 27%
- Estonia: 26%
- Finland: 26%
- Iceland: 34%
- Ireland: 34%
- Latvia: 19%
- Lithuania: 12%
- Norway: 22%
- Sweden: 22%
- Total Northern Europe: 28%

**Southern Europe**
- Albania: 22%
- Bosnia and Herzegovina: 13%
- Croatia: 17%
- Greece: 26%
- Italy: 37%
- Malta: 0%
- Montenegro: 3%
- Portugal: 36%
- Serbia: 30%
- Slovenia: 30%
- Spain: 34%
- Total Southern Europe: 32%

**Eastern Europe**
- Belarus: 14%
- Bulgaria: 25%
- Czech Republic: 44%
- Hungary: 40%
- Poland: 3%
- Republic of Moldova: 2%
- Romania: 9%
- Russian Federation: 17%
- Slovakia: 28%
- Ukraine: 5%
- Total Eastern Europe: 16%

**Europe**
- Former East bloc: 16%
- Europe without former East bloc: 32%
- Europe total: 27%

*Note: The graph shows the population prevalence per 10,000 persons for each country.*
Notes

a. 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 different European countries, 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 (available for 8 countries), and with data on the distribution of age at death of people with DS from national statistics (available for most countries). For former West bloc countries, the projections matched the empirical data. However, the model had a very poor fit with empirical data from former East bloc countries. We developed an alternative model of survival for the former East bloc countries, with a less favorable survival of people with DS up to 2000. Projections of this alternative model had a far better match with the empirical data. Further details are available in our paper and supplementary materials.[1]

b. Data on live births of children with Down syndrome were based on EUROCAT Registry of Congenital Anomalies and published results of estimates for some countries. It is important to realize that for many countries there is some uncertainty in the estimates of actual LB prevalence due to incompleteness of data. Sources and uncertainties are detailed in the supplementary information available with our paper.[1]

References


Other population factsheets available

USA:
https://go.downsyndromepopulation.org/usa-factsheet

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

New Zealand:
https://go.downsyndromepopulation.org/new-zealand-factsheet

Table 1. The estimated number of people living with Down syndrome in European countries in 2015