Factors influencing birth rates of babies with Down syndrome

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Many factors influence reproductive choices, including personal beliefs and value systems, wealth and income, and the availability of healthcare and reproductive services.

Since the late 1960s, prenatal screening for Down syndrome has been introduced in many countries and, over time, new screening tests have become available and have been increasingly incorporated into antenatal care. These changes appear to have impacted the birth rates of babies with Down syndrome substantially in many countries.[1-7] But, to what extent have different factors influenced birth rates? We set out to explore this question with a methodical analysis of data[8] from 33 countries.[9]

What did the study do?

We examined how changes in prenatal screening policies, along with national demographics and economic conditions, are associated with the share of pregnancies with Down syndrome that do not result in a live birth because of selective termination following prenatal testing (the "reduction percentage").

We analyzed data[8, a] from 33 countries (covering the years 1991 to 2020). We examined year-to-year changes within each country to try to identify how different factors influenced reduction rate (in %).[9]

What did the study find?

Making screening available and reimbursing the costs has the largest association with reductions

When a country moves from no screening to serum screening[b] with reimbursement, the odds of a reduction increase by a factor of 3.24. Put another way, a country with a baseline reduction of 25% would be expected to see that rise to about 52%, holding all other variables constant (Figures 1 and 2).

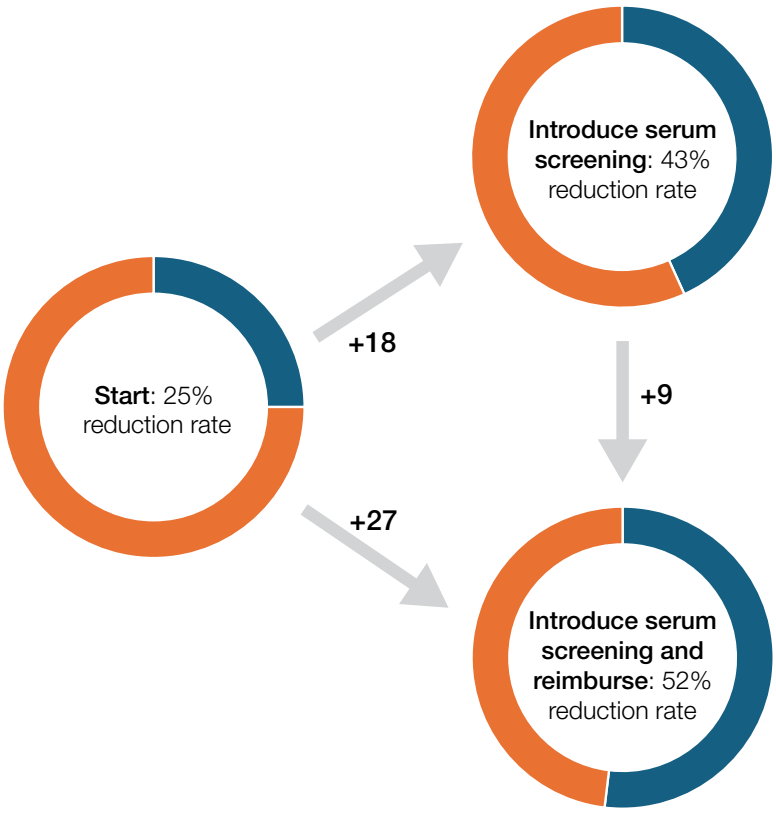


Figure 1. **Effects on reduction rates associated with the introduction of serum screening[b], given a starting reduction rate of 25%.** (Note: the effects will be different for different starting reduction rates)

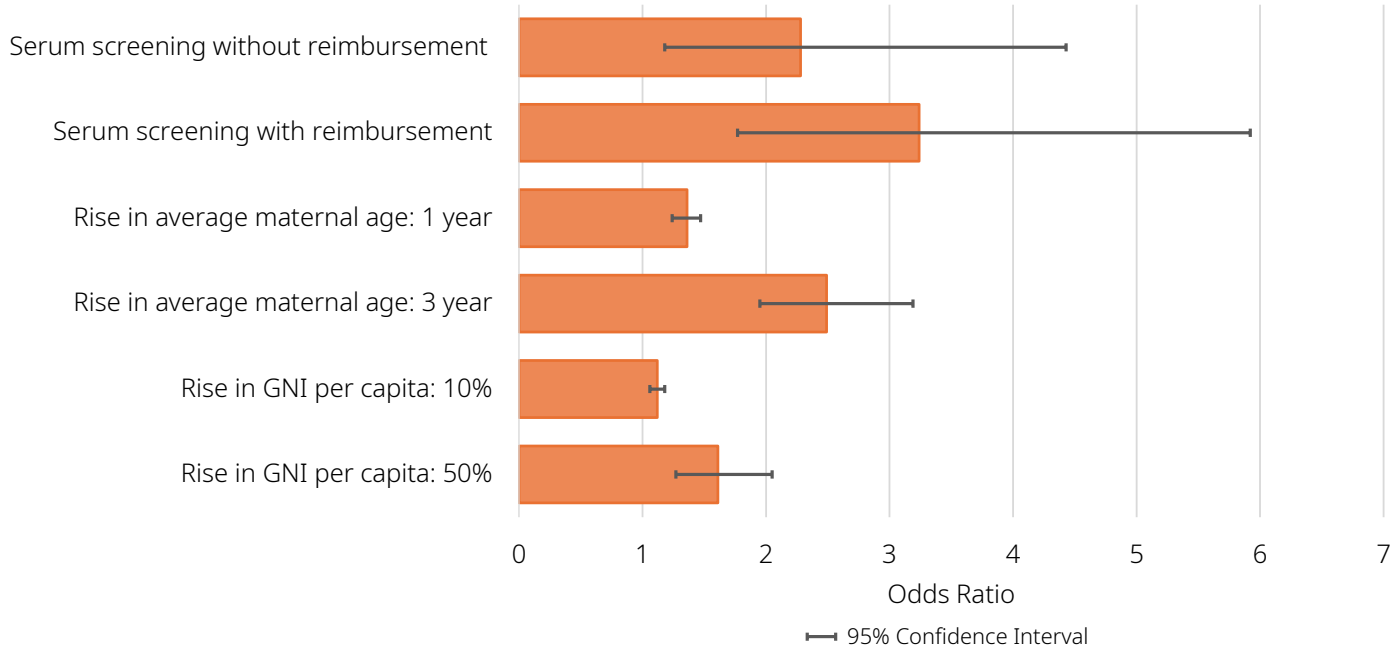


Figure 2. **Relative effects of different factors on the odds of reduction.**

Availability of screening is associated with reductions even without reimbursement

When a country moves from no screening to serum screening[b] *without* reimbursement, there is a moderate increase in reductions (odds ratio 2.28). Put another way, a country with a baseline reduction of 25% would be expected to see that rise to about 43% (Figures 1 and 2).

While, perhaps unsurprisingly, the introduction of serum screening tests within a country increases reduction, the larger increase when reimbursed suggests that screening choices are not only influenced by the *availability* of screening tests, but also by the *costs* of the tests paid by parents.

This may also imply that, in countries where costs are not reimbursed or where reimbursement is dependent on insurance coverage, reduction rates will be higher among wealthier parents and lower among more disadvantaged parents.

Rising maternal age is associated with reductions

When the average maternal age of mothers in a country increases by 3 years, the odds of a reduction increase by a factor of 2.49 (Figure 2). Put another way, a country with a baseline reduction of 25% would be expected to see reduction rise to about 45%.

This finding may be explained by older mothers being more inclined to opt into screening due to their higher risk of a pregnancy with Down syndrome.

National income per head is associated with reductions

When national income per head increases by 50%, the odds of a reduction increase by a factor of 1.61 (Figure 2). Put another way, a country with a baseline reduction of 25% would be expected to see reduction rise to about 35%.

This suggests that either citizens of higher-resourced countries are (a) more likely to access prenatal services even when they are not reimbursed by their governments (due to fewer financial barriers to the supply and demand of prenatal services), (b) less likely to place value on children with Down syndrome, or (c) some combination of both.

Religious belief and abortion views do not appear to be associated with reductions

The study did not find evidence that religious beliefs or views about abortion were associated with reduction rates. This may be because these views do not change much over time, or because the ways in which they change are similar to other stronger variables, or because they are just poorly measured. Alternatively, it might indicate that the views about religion and ethics reported by citizens in surveys are not reflective of their actual reproductive choices.

What does the study tell us about future populations of people with Down syndrome?

Insofar as past factors associated with reductions in the rates of births of babies with Down syndrome are predictive of the future, we can anticipate that further increases in the availability and reimbursement of prenatal screening services around the world will continue to increase overall reduction rates. Additionally, rising average maternal age and incomes will further contribute to increases in reduction rates (although rising average maternal age is also increasing the numbers of babies expected to be born in the absence of screening). It is unclear how future changes in views about religious beliefs and the ethics of abortion might influence future reduction rates.

Babies with Down syndrome continue to be born

It is important to note that – even with widespread availability of prenatal screening services in wealthy countries – reduction rates vary, and many babies with Down syndrome are still born.

In northern, western and southern Europe, reduction rates are around 51%, 59% and 72%, respectively.[5] In Canada, Australia and New Zealand, reduction rates are around 53%, 66% and 71%.[6,7] In the USA, reduction rates are around 37%.

The expected live birth prevalence of Down syndrome is rising in many countries due to rising average maternal ages. Therefore, even with substantial reduction rates, across Europe, the USA, Canada, Australia and New Zealand, around 14,000 babies are born with Down syndrome each year, of whom around 5,000 are born in the USA.[2,4-7]

Meanwhile, many people with Down syndrome are living longer than ever before and in many of these countries, the overall populations of people with Down syndrome have not yet peaked.

What are the study's limitations?

The study focuses on changes within countries over time. It cannot determine what drives differences between countries, and unmeasured factors (for example, counseling quality or legal frameworks) may still play roles.

Additional resources

We have published a series of papers looking at births and populations in many countries[1-7] and documenting screening practices.[8] We have also published a series of facts heets to accompany our studies:

- **USA**: https://go.downsyndromepopulation.org/usa-factsheet
- **Europe**: https://go.downsyndromepopulation.org/europe-factsheet
- **Australia**: https://go.downsyndromepopulation.org/australia-factsheet
- **New Zealand**: https://go.downsyndromepopulation.org/new-zealand-factsheet
- **Canada**: https://go.downsyndromepopulation.org/canada-factsheet
- **Latin America and the Caribbean**: https://go.downsyndromepopulation.org/latin-america-caribbean-factsheet

Notes

a. Country-specific screening policies are detailed in the Supplementary Materials to [8], which are available at: https://go.dselink.net/d72h

b. In our study, "serum screening" includes prenatal cell-free DNA testing (previously referred to as non-invasive prenatal testing NIPT or screening NIPS), together with other serum screening tests.

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