

Special educational needs provision in primary schools for children with major congenital anomalies

Evidence from the ECHILD Database

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This Data Insight draws on the Education and Child Health Insights from Linked Data – England (ECHILD) database. It describes the prevalence of recorded special educational needs (SEN) provision (see Box 1) in primary school for children born with a range of abnormalities in England. It also examines the change in proportion of children with recorded special educational needs provision before and after changes to the special educational needs system in England in 2014.

Specifically, we describe the proportion of children with SEN provision recorded in primary school when they are aged five to eleven years. We present results for children born with different types of major congenital anomalies in England, which are identified using hospital records. We also document the change in the proportion of children with recorded SEN provision in year 1 (ages five to six years) before and after reforms to the SEN system in 2014.

This is important for providing information for families and clinicians, supporting planning of SEN provision, and monitoring changes to SEN provision over time.

Background

For every hundred children born in England, between two and three have one or more major congenital anomaly. These are abnormalities that are present before birth and include conditions such as cleft lip and palate, spina bifida, Down syndrome and heart defects.

Children with major congenital anomalies tend to have complex health problems, meaning that they are likely to require additional support from health and education services as they grow up. However, there is a lack of information about the number of children with specific major congenital anomalies who receive support in England, particularly in the education system.

Box 1: What is special educational needs (SEN) provision?

SEN provision is the system for supporting children who require extra help with learning at schools in England. We looked at three categories of SEN provision in this study:

- **SEN support**, which is arranged by the school and includes additional support in the classroom, such as different educational materials or one-to-one assistance.
- **Education, health and care plans (EHCPs)**, which are legal documents arranged by the local authority for children who need more support than that available through SEN support, such as extra one-to-one classroom support or therapies outside school.
- **Attendance at specialist provision**, including special schools (where most children have an EHCP) and alternative provision (where about 80% of children have SEN support or an EHCP). Support offered through this provision differs from mainstream school, including smaller classroom sizes and an adapted curriculum.

The 2014 special educational needs reforms

The 2014 SEN reforms refer to changes to the provision of help for organisations working with children and young people with SEN and disabilities (SEND). These changes were brought about by the Children and Families Act and SEND code of practice 2014.

Principles of the reformed system included:

- earlier identification
- participatory decision-making
- a delegated SEN budget for schools
- changes to the categories of SEN provision offered to children (SEN support replaced School Action or School Action Plus and EHCPs replaced statements of SEN).

What we did

ECHILD joins together existing, de-identified health, education and social care information for approximately 20 million children in England. In this study, we used hospital and school records from the ECHILD database for all children who were born in England between 1 September 2003 and 31 August 2013 (see **Figure 1**). We identified major congenital anomalies using diagnoses in hospital admission records in the first year of life. We also linked in information on school type (mainstream, special school or alternative provision) using the Department for Education’s [“get information about schools” database](#).

For children with and without a major congenital anomaly, we calculated: the proportion of children with SEN provision recorded at any point during primary school (when children were aged between five and eleven years); and the difference in proportion of children with SEN provision recorded in year 1 (aged five to six years) before and after the 2014 SEN reforms. In England, year 1 is the first full year when all children must attend school.

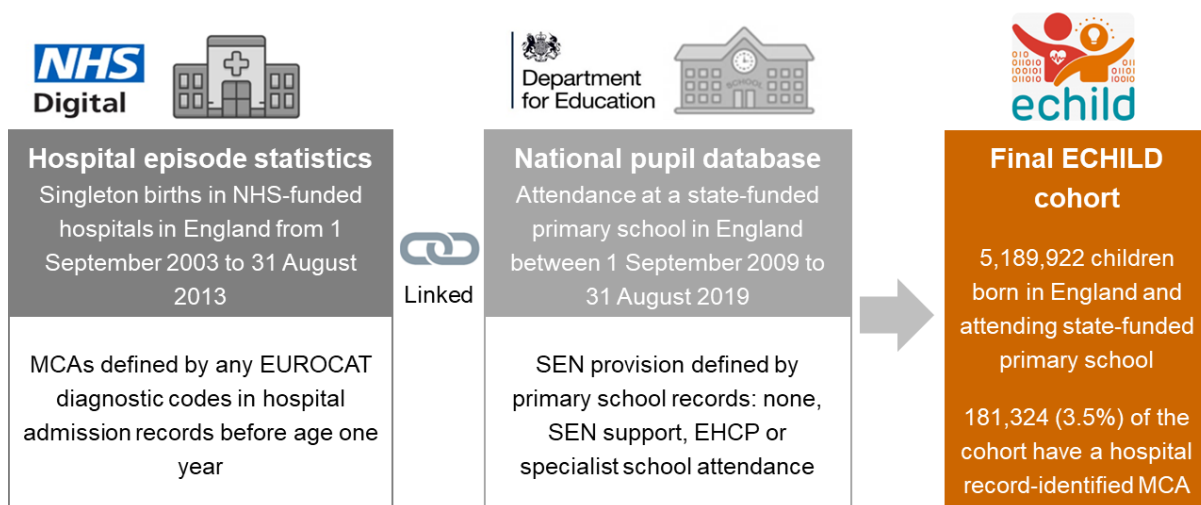


Figure 1. Components of the ECHILD database used in this study.

- EUROCAT = European network of population-based registries for the epidemiological surveillance of congenital anomalies.
- EHCP = education, health and care plan. MCA = major congenital anomaly.
- NHS = National Health Service.
- SEN = special educational needs.

(Alternative text is provided in the appendix).

What we found

Children with a major congenital anomaly were more likely to have SEN provision

Two in five children with a major congenital anomaly had any recorded SEN provision in primary school between 2008 and 2019 – almost double the proportion found in peers without one of these conditions (see **Figure 2**). The proportion of children with a major congenital anomaly who had an EHCP in mainstream school, or who attended a specialist school, was more than four times that for children without a major congenital anomaly.

The proportion of children with SEN provision varied by type of major congenital anomaly

Almost all children with chromosomal anomalies (such as Down syndrome and Turner syndrome) had some type of SEN provision recorded in primary school, and eight of every ten of these children had an EHCP in mainstream school or attended a specialist school.

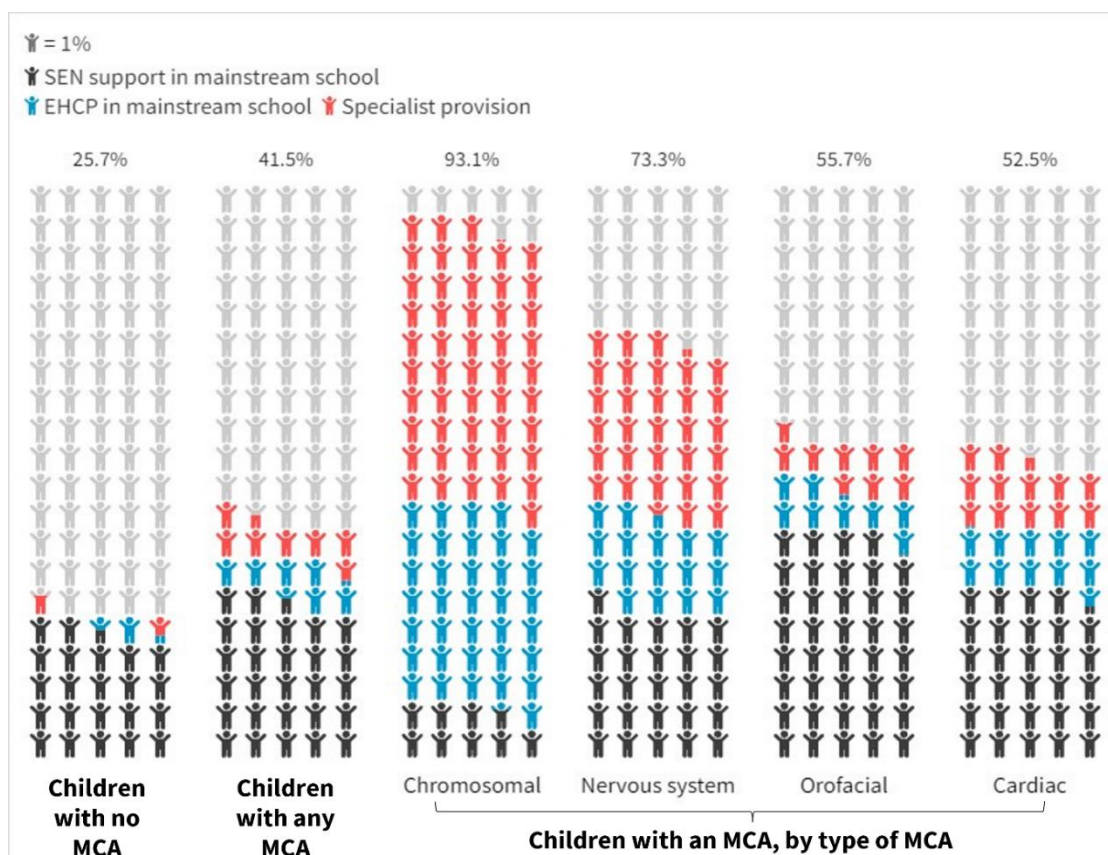


Figure 2. The proportion of children with SEN provision recorded in primary school. EHCP = Education, health and care plan. MCA = major congenital anomaly. SEN = special educational needs. (Alternative text is provided in the appendix).

The proportion of children with SEN provision decreased after 2014

Overall, about one in twenty fewer children had SEN provision in year 1 after 2014. This decrease was driven by a reduction in SEN support in mainstream schools (**Figure 3**). The change was similar for children with and without a major congenital anomaly.

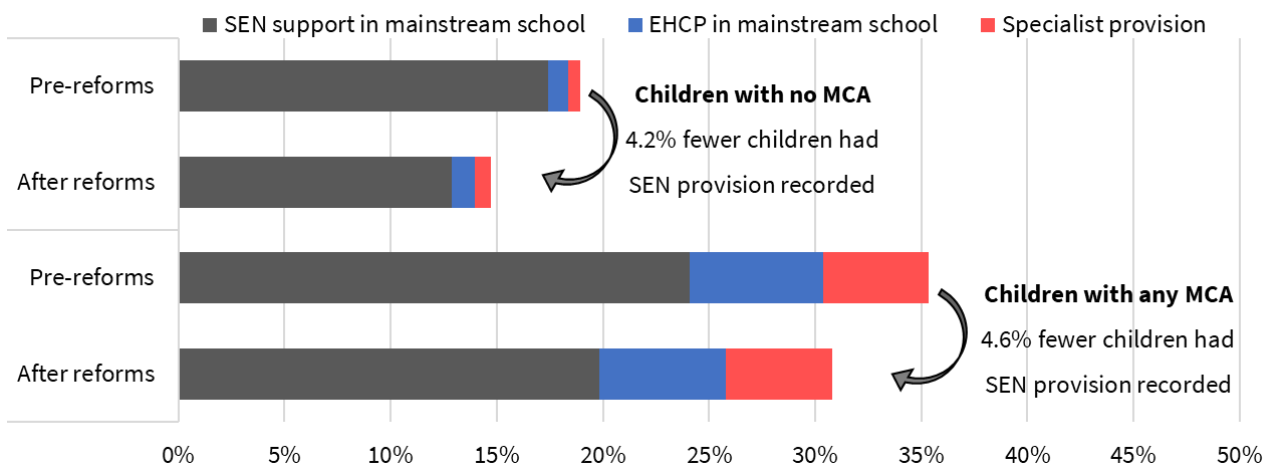


Figure 3. Proportion of children with recorded SEN provision in year 1 before and after the SEN reforms.

- EHCP = Education, health and care plan.
- MCA = major congenital anomaly.
- SEN = special educational needs.

(Alternative text is provided in the appendix).

Why it matters

Families, service providers and clinicians want information about whether children with a major congenital anomaly are likely to require SEN provision, in order to plan for schooling. We show that the likelihood of SEN provision in primary school varies by type of major congenital anomaly identified in hospital records.

This work illustrates how large administrative datasets can be harnessed to provide such information. The approach in this study could be developed to use de-identified ECHILD data routinely for planning and monitoring of SEN provision. For example, the need for early specialised support could be identified in hospital episode statistics by the end of infancy. This information could then be shared with each local authority. Specialist paediatric services could use such information to prepare parents for the type of support likely to be needed.

Importantly, this work also shows that early SEN provision (in year 1, by age six) has reduced over time, particularly for children at the lower level of support.

What next?

Further research is necessary to assess the quality and variability of SEN provision across England, particularly as the quantity of SEN provision has been reducing over time. In particular, some health and education professionals worry that SEN provision is a "postcode lottery" in England. This means that access to support might vary depending on where children live, rather than according to their needs.

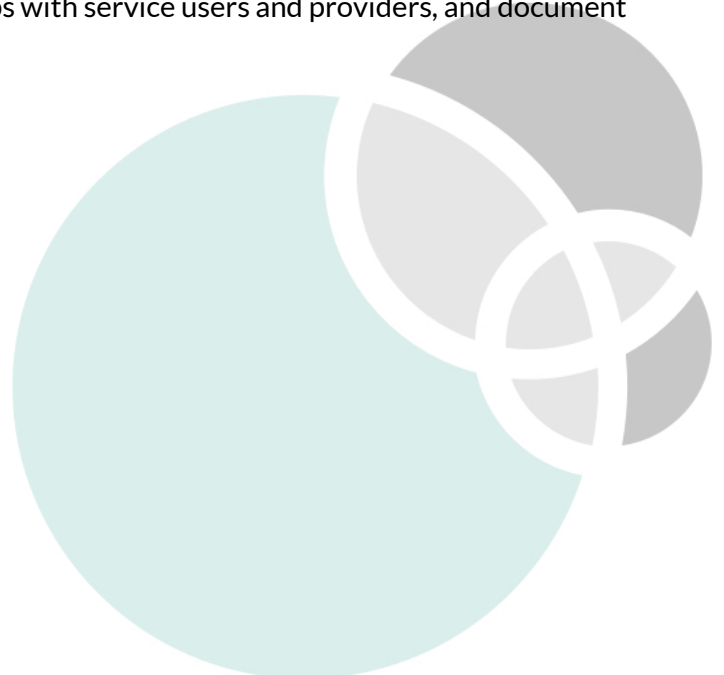
Next, we will investigate whether the chance of a pupil with similar characteristics getting special educational needs provision in schools is the same across different parts of England. We will also explore whether characteristics of local areas and schools contribute to differences in provision across regions in England. The results will help us to understand whether special educational needs provision is equal across England and inform policies to best support children.

Notes

This work is part of a wider project called the [Health Outcomes for People in Education \(HOPE\) study](#), which aims to investigate the impact of adjustments for SEN on children's health and education outcomes using mixed methods. Other work in HOPE also draws on ECHILD to:

- define a range of "health phenotypes", meaning health conditions identifiable in hospital records, which are expected to need SEN provision
- apply quasi-experimental methods (methods which evaluate the impact of an intervention) to work out whether getting special educational needs provision has an impact on attainment, rates of school absences or hospital contacts for children.

In addition, the HOPE study uses mixed methods to understand variation in policies and in identification, assessment and provision for SEN, and how families experience these processes. These methods include surveys, interviews and focus groups with service users and providers, and document analyses.



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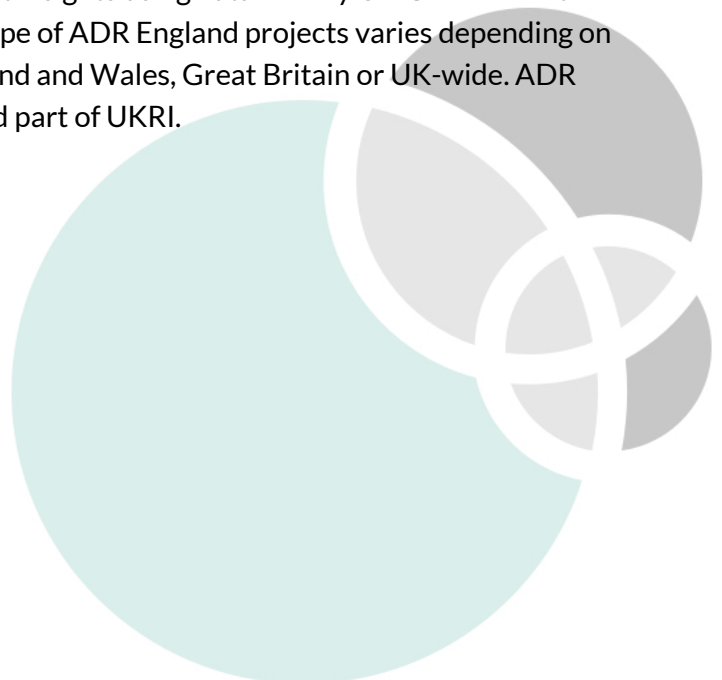
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Appendix: Alternative text

Figure 1:

Diagram showing the different datasets in ECHILD used in this study, with a final cohort of more than five million children. Text reads:

“Hospital episode statistics: Singleton births in NHS-funded hospitals in England from 1 September 2003 to 31 August 2013. MCAs defined by any EUROCAT diagnostic codes in hospital admission records before age one year.”

Graphic shows that this is linked to:

“National pupil database: Attendance at a state-funded primary school in England between 1 September 2009 to 31 August 2019. SEN provision defined by primary school records: none, SEN support, EHCP or specialist school attendance.”

An arrow points to:

“Final ECHILD cohort: 5,189,922 children born in England and attending state-funded primary school. 181,324 (3.5%) of the cohort have a hospital record-identified MCA.”

Figure 2:

Pictogram of the proportion of children with SEN provision, where children with a major congenital anomaly have almost double the proportion compared to children without SEN provision.

Figure 3:

Bar chart showing that the proportion of children with SEN provision reduced after SEN reforms for children with and without a major congenital anomaly.