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# Evaluation of special educational needs and disability provision in English primary schools using administrative health and education data in the ECHILD database

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## Abstract

### Introduction
Schools worldwide balance whole-class teaching with additional provision for children with special educational needs or disability (SEND). Robust evidence on equity and effectiveness of SEND provision is essential to address growing demand and rising costs globally.

### Objectives
To synthesise findings from the Health Outcomes for young People throughout Education (HOPE) evaluation of variation in SEND provision and its impact on health and education outcomes in English primary schools. We integrated findings from 14 sub-studies using administrative data in the Education and Child Health Insights from Linked Data (ECHILD) database and 10 mixed methods sub-studies.

### Methods
Analyses of ECHILD data followed children from birth to age 11 years. We examined how variation in SEND provision was associated with health conditions, and school, social and organisational factors. Using target trial emulation, we estimated the impact of SEND provision on hospital admissions, school absences and attainment. We surveyed and interviewed young people, parents, and professionals and reviewed information about services to understand SEND processes and contexts.

### Results
Of 3.8 million children born 2004 to 2013, 30% had SEND provision recorded by age 11. Health conditions were only partially associated with SEND provision, which was also related to male gender, social disadvantage, low attainment and type of school. SEND provision modestly reduced rates of unauthorised absences in subgroups of children but showed no measurable benefit on hospital admissions or school attainment. Mixed methods studies highlighted benefits of early, responsive support, challenges posed by limited capacity, harms caused by delayed or inadequate provision, and need for parent advocacy to access SEND provision.

### Discussion
Weak evidence of benefits of SEND provision in causal analyses likely reflects unmeasured confounding, lack of measures of provision received and insensitive outcomes in ECHILD data. SEND policies need robust evidence from analyses across jurisdictions using administrative data, enhanced with better measures, experimental methods and contextual evaluation.

### Keywords
'special education'; disability; administrative health data; linked administrative data; causal inference

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# Background

## Special educational needs

Education systems worldwide need to balance delivery of effective mainstream education with additional activities or support for children who experience difficulties with learning compared to their peers [1]. In this study of the English context, we refer to such additional support as special educational needs or disability (SEND) provision (see Appendix 1, Table A1 Section 5) [2]. Typically, SEND provision involves a wide range of types and intensity of activities, from continuous one-to-one support to occasional group work, across various types of needs. Activities change as the child responds and develops [3]. SEND provision also includes collaboration between multi-sector professionals and families, all within a complex, publicly funded system [4, 5].

Children likely to need SEND provision include those with disability, preterm birth or chronic physical or mental health conditions that affect learning [5–7]. In many countries, children with behaviour problems, speech or language difficulties, low school attainment, social disadvantage, and those who speak a different language are also assigned SEND provision [1]. Countries worldwide report rising demand and increasing costs of SEND provision, reflecting improved survival among children with medical conditions, increasing recognition of neurodevelopmental disorders, and global efforts to expand educational access and provide inclusive education for all [8–10].

## Purpose of this report

This paper provides an overview of the Health Outcomes of young People throughout Education (HOPE) study and synthesises findings of sub-studies conducted by the programme [11]. The aim of the HOPE study was to examine variation in SEND provision in English primary schools and assess its impact on children's health and educational outcomes articulated across four main questions [11]. We conducted 12 quantitative studies using linked health and education administrative data from the Education and Child Health Insights from Linked Data (ECHILD) database [12] and 10 mixed methods studies. Comprehensive descriptions of methods and results can be found in 30 papers listed in Appendix 4.

We organised the paper as follows. First, we summarise existing evidence on the effectiveness of SEND provision and outline SEND policy and practice in England. Second, we give an overview of the HOPE study questions and methods - including the ECHILD data resource and how we derived cohorts and synthesised findings. Third, we report findings for each of four research questions and present key findings. Fourth, we present our conclusions on variation in SEND provision and its impact on outcomes and discuss strengths and limitations of the study. We end by discussing challenges posed by administrative data relevant globally and the implications of our findings for policy and future research.

## Existing evidence on the effectiveness of SEND provision

In England, SEND provision seeks to support four broad areas of functional needs: communication and interaction, cognition and learning, social, emotional and mental health, and sensory and physical needs [13–15]. These needs often arise from physical or mental health conditions or from social contexts that affect areas of child development [5, 6, 16, 17]. High quality SEND provision has the potential to improve health and education outcomes in childhood, and thereby health and wellbeing in adolescence, with long-lasting impacts on health and economic inequalities in adulthood [6, 18–20]. However, evidence for effective SEND provision is mixed.

On the one hand, an international systematic review of 467 comparative studies of children with known additional needs (including 297 randomised controlled trials; RCTs), reported consistent beneficial effects of different types and durations of SEND activities compared with service as usual or alternative education activities [4, 21]. On average, these benefits equate to 5 to 6 months of improved learning in maths, reading, or related skills. Most studies included in the review were focused on targeted activities for well-defined learning difficulties (e.g. 40% were for dyslexia), rather than evaluating SEND provision across the breadth of usual practice [22]. In addition, the impact of these targeted interventions, assessed under controlled research conditions, may not generalise to the complex, interdependent processes through which SEND provision operates in real-world school settings. Few studies have accounted for the underlying health conditions and health inequalities that shape both the need for, and the outcomes of, SEND provision.

Evidence for the effectiveness of SEND provision as delivered in schools is more limited than the evidence base for targeted interventions. SEND provision as a service involves a variety of interventions for a wide range of different needs. The delivery of SEND services intersect with socioeconomic position and family factors, health, social care services, and local service capacity. Such complex processes are hard to evaluate. So far, limited evidence of benefit has been reported by numerous observational studies over the past 25 years. As expected, descriptive studies found that children assigned SEND provision had worse outcomes than peers, due to confounding by higher underlying health and education needs [16, 22, 24]. However, 49 studies that attempted to account for confounders using quasi- or natural experimental designs, also found no difference or worse outcomes for children assigned SEND provision [22, 23, 26–30]. Similarly adverse findings were reported in an evaluation of teaching assistants in England, a group who are typically involved in delivering SEND provision [31].

Recent advances in causal methods are presented as a framework for using natural experiments, also called quasi-experimental methods, to evaluate population health interventions [32, 33]. The framework refers to a range of methods to achieve comparability (or exchangeability) between those with and without intervention. Various methods can be used to account for measured confounding, including those within the target trial emulation framework (TTE)

[32, 34]. Methods often used to address unmeasured confounding include difference-in-difference and instrumental variable techniques. A meta-analysis of 44 U.S. studies that tried to minimise confounding found eight studies that addressed the bias arising from unmeasured confounding [28]. These studies used policy changes [35, 36], or changes within children's SEND status over time [37, 38], or differential SEND thresholds across racial groups, in natural experiment approaches [35, 39, 40]. All eight found effects of SEND provision: five reported beneficial impacts, while three reported harmful effects for certain subgroups. For example, two studies found worse outcomes for children who were just below the threshold for SEND provision who received provision due to policy changes [39–41]. These effects for marginal groups might not be generalisable to all children who need SEND provision.

In summary, uncertainty remains about the benefits of SEND provision as delivered in routine practice globally, as well as in England. At the same time, there is strong evidence that targeted activities, delivered as key elements of the SEND process, are effective, albeit often for narrowly defined needs and outcomes [9]. Policy makers need robust evidence on what types of SEND provision work, for whom, and under what conditions, and on the effectiveness of the overall SEND process, to deliver effective support while containing costs. Applying robust study designs to linked administrative health and education data provides a unique opportunity to fill these evidence gaps.

### SEND policy and provision in England

Despite the uncertain evidence [2, 42], England has seen major policy changes to funding and delivery of SEND provision over recent decades, which offer opportunities for natural experiment designs that address unmeasured confounding. Since 2001 [43], policy has shifted towards inclusion of children receiving SEND provision in mainstream education. The Children and Families Act (2014) [2], and the SEND Code of Practice (2015) [3], aimed to improve SEND joint working with health and social care services and devolved decisions and funding for less intensive SEND provision to schools. However, schools were challenged by a more competitive, attainment-focused, marketisation of education that disincentivised inclusion of children unlikely to perform well in attainment tests. In 2022, a House of Lord's review of the 2014 Act concluded the government had 'ultimately failed' to improve outcomes, due to failure of implementation [44].

Implementation of the 2014 Act coincided with two broader system shifts. Austerity-related cuts to local authority (LA) budgets from 2010 reduced SEND and social care funding, and expansion of academy schools from 2007 drove competition between schools and widened inequalities in SEND provision between schools [8, 45]. Analyses using English primary school education data showed that the primary school a child attends is a stronger predictor of SEND provision over any personal or family characteristics [25].

SEND provision affects a substantial minority of children in England. One-third of all children in state school in Year 1 in 2005/6 had been assigned SEND provision by age 16 [11]. Approximately 30% of all children were assigned SEN Support, which is determined and delivered by schools. Since then, between 3-5% of all children have been assigned an Education, Health and Care Plan (EHCP), which is assessed, approved and part-funded by local authorities (Appendix 1 Table A1, Section 5) [3]. SEN Support typically includes in-class assistance, teaching aides or adaptive learning, while EHCPs provide tailored and personalised support for more complex needs. Approximately half of all children who receive an EHCP attend a special school [3]. Since 2010, the proportion receiving SEN Support has declined, while use of EHCPs has risen steadily since 2016, driving annual SEND expenditure in England above £11 billion in 2025 [8, 42]. Further reforms to the SEND provision system will be published by the Department for Education (DfE) in 2026 [46, 47].

## Overview of methods used in the HOPE study

### Research questions and approach to synthesis

The HOPE study aimed to examine variation in SEND provision in English primary schools and assess its impact on children's health and educational outcomes [11]. We addressed four main research questions and consulted with young people, parent-carers and professionals throughout the study (Appendix 2):

> **Question 1:** Which health conditions (phenotypes) are associated with outcomes that might be improved by SEND provision?
>
> **Question 2:** What factors influence who is assigned SEND provision, and when and where this occurs?
>
> **Question 3:** What is the impact of SEND provision on health and education outcomes?
>
> **Question 4.** What do service experiences and policies tell us about the process and delivery of SEND provision?

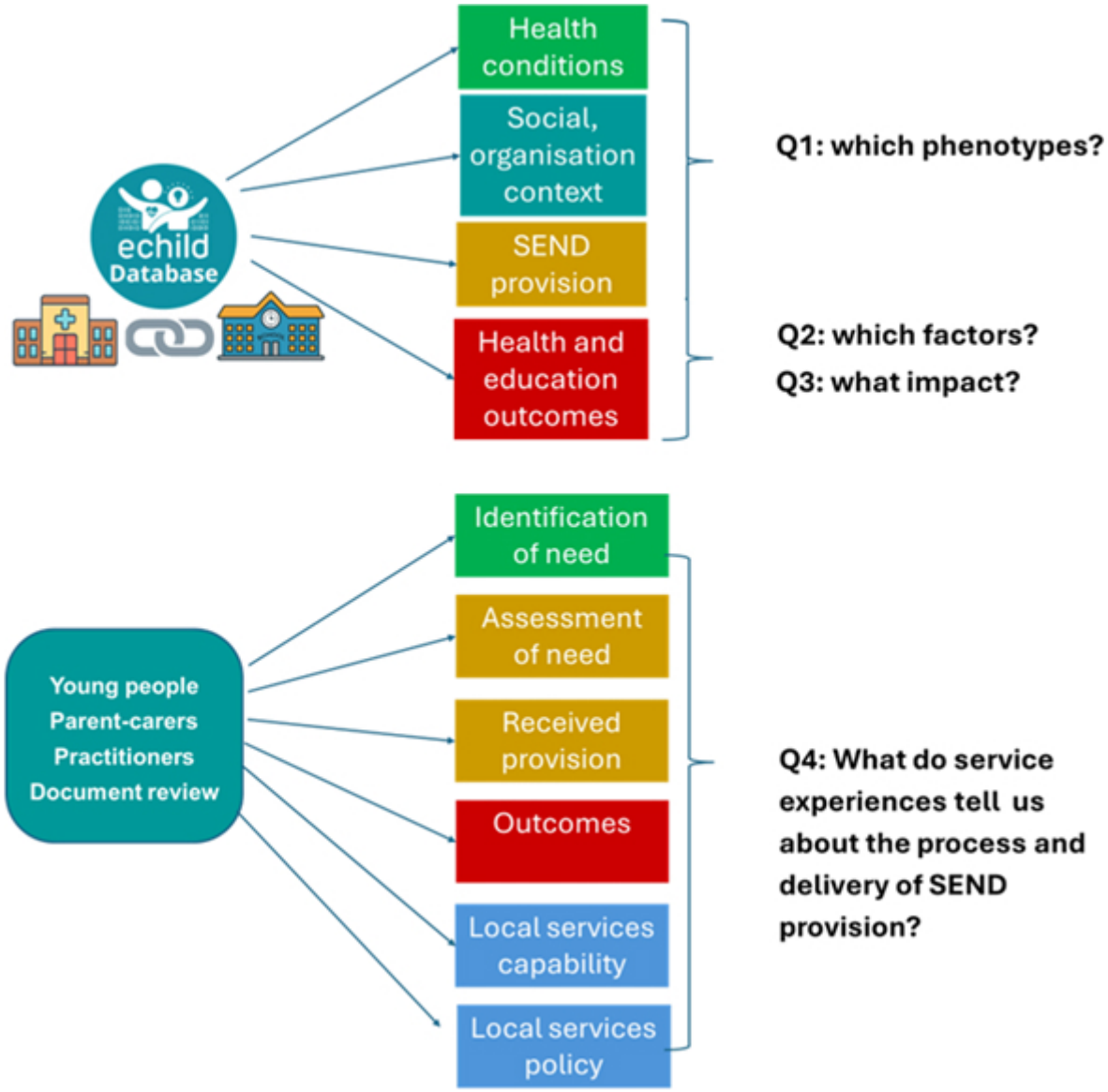
We used the ECHILD (Education and Child Health Insights from Linked Data) database to address the first three questions and mixed methods studies to address the fourth (Figure 1). Details of data resources are in Appendix 1, Table A1, sections 4-6.

We synthesised findings from the sub-studies addressing the four research questions through an iterative process. First, researchers integrated findings within each individual question. Then, teams working on each question shared their results throughout the study to summarise common and contrasting emerging themes across all four research areas and to identify issues for further discussion with stakeholders (see Appendix 2). We generated conceptual diagrams to map findings between studies (e.g. Figure 7). In the final stage of synthesis, we met public and professional and government stakeholders to discuss the implications of findings (Appendix 2).

### The ECHILD Database

The HOPE study used the ECHILD data database for the 12 sub-studies addressed by research questions 1 to 3 listed above. The ECHILD database links routinely collected health

Figure 1: Diagram of data sources used to address the questions posed by the HOPE study




and education data in England. For the HOPE study we used ECHILD version 1, which includes all children and young people aged 0-24 years who were born in a state-funded hospital between 1 September 1995 and 31 August 2021 (approximately 14.7 million individuals) [12]. Health and education datasets were linked by National Health Service (NHS) England using a multistep deterministic linkage algorithm [48]. Linkage rates were high and increased overtime (92% of school pupils born in academic year 1990/1991 were linked to a hospital record, compared with 99% of pupils born in 2004/2005) [48].

Health data from the Hospital Episode Statistics (HES) database includes records of all NHS-funded hospital care in England. We created birth admission cohorts from 1 September 2003 onwards as linkage to subsequent admissions, outpatient appointments and accident and emergency attendances was high from this point onward. HES admissions include birth records for approximately 97% of all children who are born in NHS facilities and captures an estimated 98–99% of all secondary care contacts [11, 49, 50]. HES records contain demographic details (e.g., sex, ethnic group, area of residence) and admissions data include clinical information based on International Classification of Diseases, 10th Revision (ICD-10) diagnostic codes and Office of Population Censuses and Surveys, 4th Revision (OPCS-4) procedure codes [50].

Education data from the National Pupil Database (NPD) capture information on children attending state-funded schools in England from the 2001/02 academic year onwards [51]. The NPD includes pupil registration, attainment, exclusions, and absences, alongside individual- and school-level characteristics such as local authority, ethnicity, gender, Index of Multiple Deprivation (IMD), English as a first language, free school meal eligibility, social care involvement, and SEND status [11, 51]. Further details are in Appendix 1, Table A1, Sections 4–6.

## Birth cohorts in the HOPE Study

Ten birth cohorts were constructed from ECHILD to meet the specific analytic needs of each sub study (Table 1; Appendix 3). Sub studies used longitudinal designs and spanned multiple

academic primary school years (eg: 1 September 2003 to 31 August 2004) onwards [11, 51]. Follow-up periods were defined according to each study's objective, exposure group and educational variables of interest and data availability. For example, data access for cohort 4, which was analysed at the start of the study, was limited to births in 2004/5 [52].

Most analyses using educational outcomes up to the end of primary school (Key Stage 2, aged 10-11 years) restricted birth years to the end of the 2007/8 academic year (31 August 2008). This ensured that all children had finished primary school before the COVID-19 pandemic which disrupted attendance, learning and assessments [53]. The January school census was used to identify children enrolled in each academic year, as this census determines school funding allocations and is therefore considered the most complete record of pupil enrolment [54].

## Synthesis of findings

### Question 1: Which health conditions or phenotypes are associated with outcomes that might be improved by SEND provision?

The first step of the HOPE study involved developing high-need health phenotypes to proxy groups of children likely to need SEND provision. This step is critical, as education data captures only the assignment of SEND provision but no indicators for the underlying need for additional support. Using external evidence, clinical input and insights from ECHILD data regarding the reliability of diagnostic coding in administrative data, we chose three groups of health phenotypes which capture populations with different levels of need for SEND provision: neurodisability [55], congenital anomalies [56], and preterm or early term births, defined by week of gestational age [52, 57]. These phenotypes were mainly recorded before school entry and, on average, were expected to have mild to moderate (congenital malformations) or moderate to high (neurodisability) need for SEND provision or a gradient of need by week of gestational age at birth. We described outcomes for each of these phenotypes, including variation between subgroups within each phenotype. Combinations of neurodisability and other high need health phenotypes were described for children with Down syndrome. In addition, we grouped children with any chronic health conditions in analyses of factors that influence SEND provision (Question 2, Table 1 cohorts 6,7).

We assessed health and education outcomes for children with high-need phenotypes and unaffected peers, from school entry to Year 6 (age 11) using cohorts 1 to 4 (Table 1) [52, 58–60]. Outcomes included: mortality before school start, comorbidities, planned and unplanned hospital admissions, unauthorised school absences, and whether a child reached the expected level of development, based on school test scores at ages 5, 7 and 11 (Appendix 1, Table A1. Section 6.6)

Children in each of the three high need health phenotype groups had more unplanned admissions [59, 61], more comorbidity [55, 62], more frequent absences [61], and lower attainment [58, 60, 63, 64], than their unaffected peers. As expected, there was substantial variation between phenotype subgroups (Appendix 4, papers 2-10). We illustrate these patterns by summarising results for children with neurodisability. Of 3.58 million children, 2.4% had a hospital-recorded neurodisability before age 5, rising to 3.6% by age 11 (Cohort 1) [55]. These children were admitted to hospital five to seven times more often than their peers and accounted for 15% of all hospital bed-days during primary school (for the 2.96 million children who had linked education records in primary school in Cohort 2) [61]. We also found 60% higher school absence rates and consistently lower attainment during primary school among children with neurodisability [61, 63]. At age 5, only 30% of children with neurodisability before school entry reached a 'good level of development' (GLD), compared with 58% of peers, and fewer than half met expected levels at ages 7 and 11 (Figure 2a) [63]. By the end of primary school (Figure 2a, Key Stage 2), over a third of children with neurodisability were not assessed in national attainment tests, contrasting with 6.4% of unaffected peers enrolled in school [63]. Outcomes varied significantly by neurodisability type and in each phenotype subgroup (Figure 2b) [63].

Children with congenital anomalies comprised 3.5% of 2.35 million children entering primary school (Cohort 3). Attainment varied between subgroups, with the lowest average attainment through primary school occurring among children with chromosomal or neurological congenital anomalies [64]. Average differences between children with and without congenital anomalies were small to moderate [64]. We found lower attainment across all anomaly subgroups for boys than girls [64]. Separate analyses of the whole population (Cohort 4) revealed lower attainment for each week of gestational age at birth before and after 40 weeks of gestation (Figure 3) [52].

See key findings, Table 3.

### Question 2: What factors affect who is assigned SEND provision, and when and where this occurs?

#### Who?

We followed cohorts of children with neurodisability, congenital anomalies and their unaffected peers, and children grouped by week of gestational age at birth (cohorts 2,5 and 4 in Table 1) to determine the proportion of children with any SEND provision (SEN Support and/or an Education, health and care plan - EHCP) recorded in Year 1 (age 5/6) and up to the end of Year 6 (age 10/11) [52, 55, 56]. The proportion assigned SEND provision was consistently higher among children with any chronic health condition or born preterm compared with their unaffected peers [55, 56]. Children with neurodisabilities had the highest proportion: 76% had any SEND provision recorded ever during primary school and 40% had an EHCP [55].

Substantial variation in the proportion of children with SEND provision was observed across condition-specific subgroups within the neurodisability and congenital anomaly phenotypes, and by week of gestational age at birth (Figure 3) [52, 55, 56].

We found that children with any recorded chronic health condition were more likely than peers to have SEND provision. In analyses of the whole population of children (Cohort 7, born 2006/7 to 2007/8), 18.1% of all children had at least one chronic health condition recorded; among these, 26.6%

Figure 2: Proportion of children with and without hospital-recorded neurodisability by age 5 (and subgroups) achieving nationally expected levels across primary school assessments (Cohort 3)

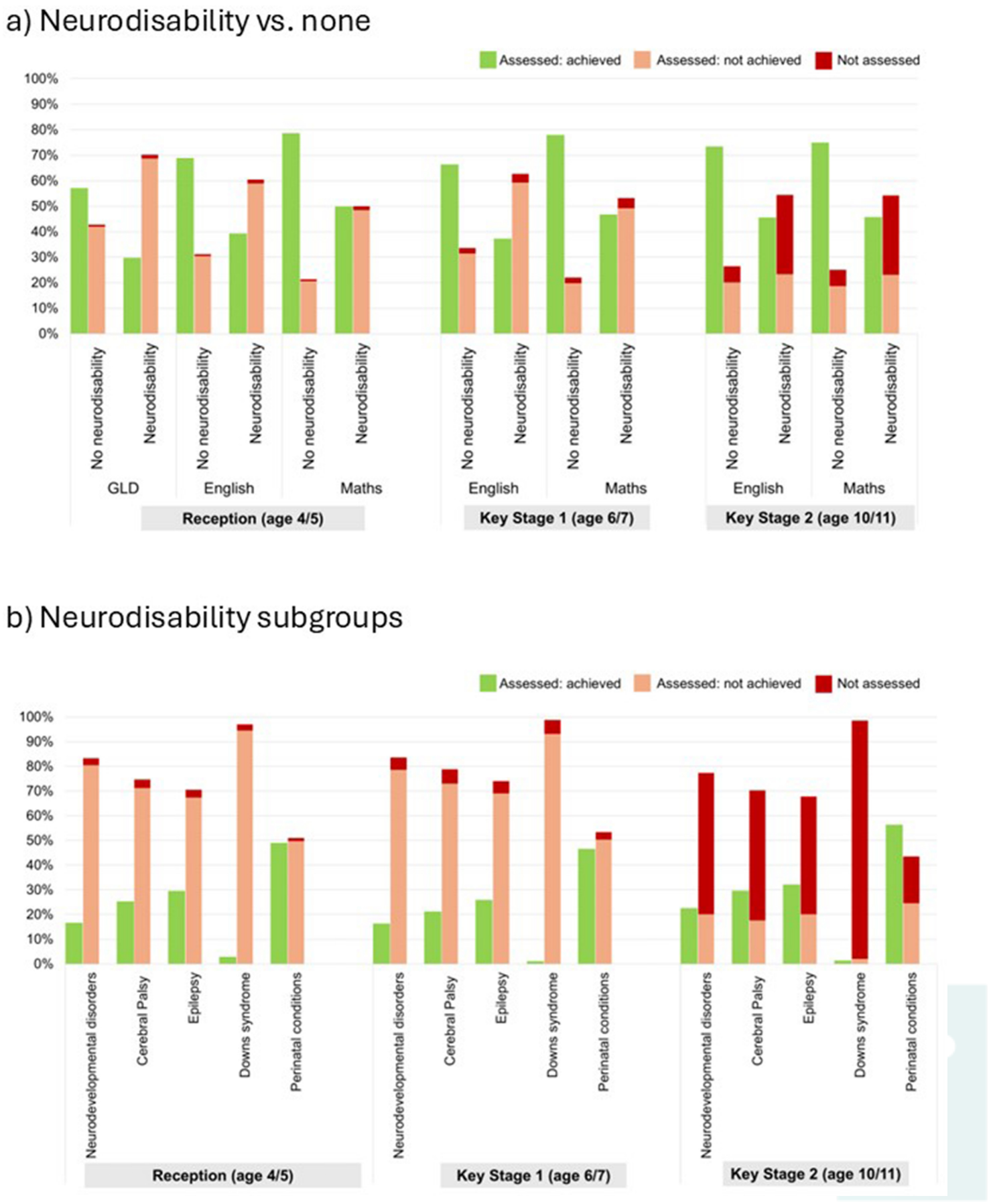


Table 1: Details of ECHILD-derived cohorts used in HOPE sub-studies* grouped by research question (see Appendix 3)

| Cohort Number | Population of Interest | Details |
|---|---|---|
| **Q1: Which health conditions (phenotypes) are associated with outcomes that might be improved by SEND provision?** | | |
| 1 | Neurodisability | 6 birth years (2003/4–2008/9)<br>No school linkage<br>N = 3,580,225 |
| 2 | Neurodisability | 6 birth years (2003/4–2008/9)<br>Y1 school entry<br>N = 2,956,299 |
| 3 | Neurodisability, Congenital Anomalies | 5 birth years (2003/4–2007/8)<br>Reception school entry<br>N = 2,351,589 |
| 4** | Gestational age across whole population | 1 birth year (2004/5)<br>Reception school entry<br>N = 306,717 |
| **Q2: What factors influence who is assigned SEND provision, when and where?** | | |
| 2 | Neurodisability | As above |
| 3 | Gestational age** | As above (used for Figure 3) |
| 5 | Congenital Anomalies | 11 birth years (2003/4-2013/14)<br>Y1 school entry<br>N = 5,189,922 |
| 6 | Whole population (excluding births before 34 weeks of gestation) | 11 birth years (2003/4-2013/14)<br>Y1 school entry<br>N = 3,729,265 |
| 7 | Whole population | 2 birth years (2006/7–2007/8)<br>Nursery 1 entry<br>N = 983,652 |
| 8 | Cerebral Palsy only*** | 10 birth years (2003/4-2012/13)<br>Nursery 1 entry<br>N = 5,669 |
| **Q3: What is the impact of SEND provision?** | | |
| 9 | Cerebral Palsy only*** | 11 birth years (2003/4-2013/14)<br>Y1 school entry<br>N = 3,275 |
| 10 | Cleft Lip and/or Palate only*** | 11 birth years (2003/4-2013/14)<br>Y1 school entry<br>N = 6,601 |

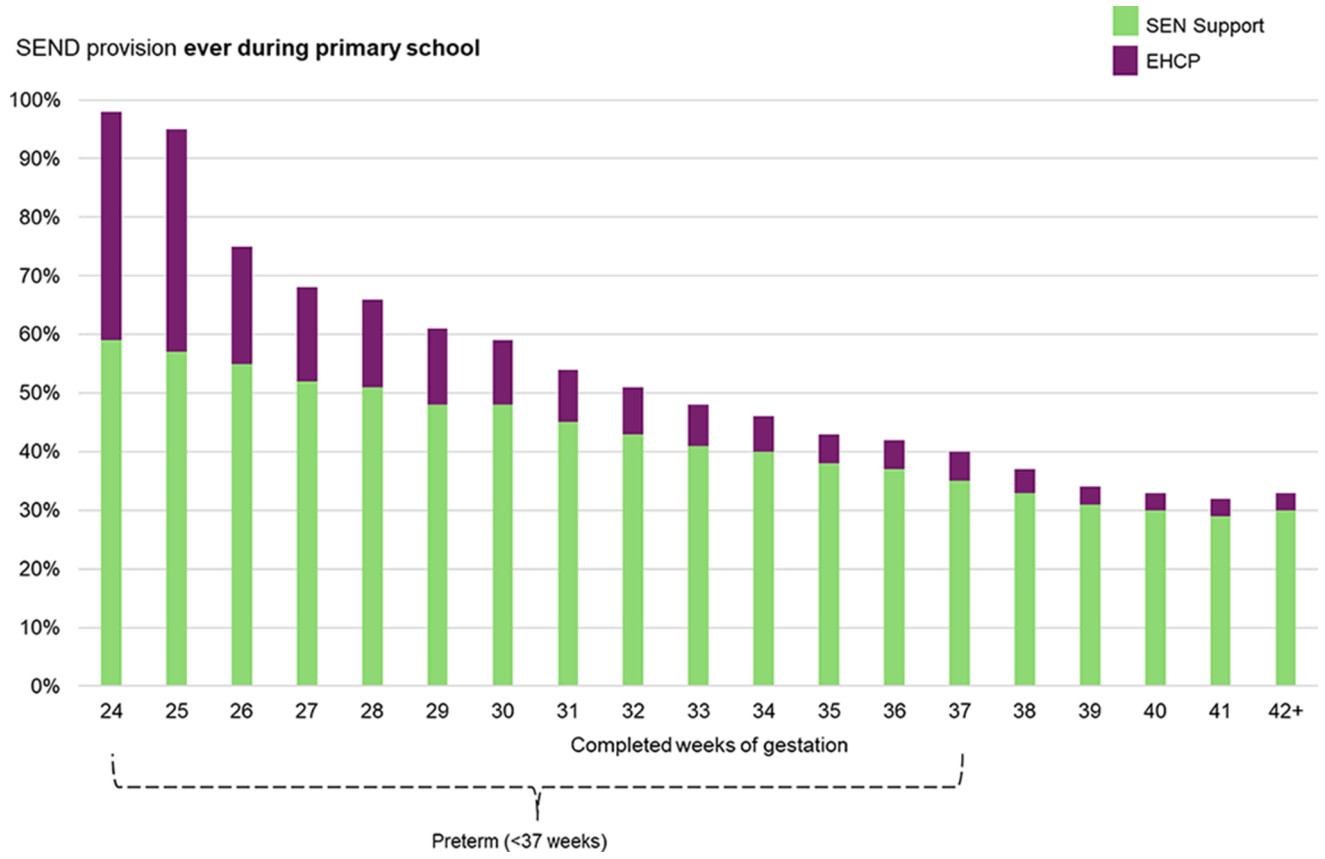
Y1: Year 1.
*Further details can be found in Appendix 4.
**Data access for this cohort used in early work was restricted to one year.
***Cohorts 8, 9 and 10 are restricted to children with the phenotype only. All other cohorts include children with phenotype and unaffected peers.

received any form of SEND provision and 5.9% had an EHCP in Year 1. The corresponding proportions with SEND provision among those without a chronic health condition were 13.4% and 0.7%. Despite this strong association, children with chronic health conditions recorded during a hospital admission accounted for only 30.5% of all children with any SEND provision and 63.9% of those with an EHCP in Year 1 [65]. These figures exclude children with chronic health conditions managed in the community without hospital admissions. Factors other than health conditions also influenced SEND provision. Socio-demographic factors were strongly associated with any SEND provision and with SEN Support: being a boy, the youngest in class (i.e. summer-born children) and being from a disadvantaged background, as measured by free school meal eligibility, young motherhood, and residence in the 40% most deprived areas. Associations between EHCP assignment and social disadvantage were weaker and less consistent, although the association with male gender remained strong [65].

### When?

We classified the stage at first entry to state education as either state-provided Nursery (school-based or local authority

Figure 3: Proportion of children assigned SEN Support or an EHCP ever during primary school by week of gestation (Cohort 3) born 2003/04 to 2007/08)




EHCP: Education and Health Care Plan; SEND: Special Education Needs and Disabilities; SEN Support: special education needs Support.

(LA) provided at age 2-4 years, N1 and N2), or state primary school Reception class (age 4/5) or Year 1 (age 5/6). We used data from the whole population of children born between September 2006 and August 2008 (Cohort 7). Overall, 42% of children began state-provided education in Nursery while 57.6% entered directly into Reception [65]. Children starting in Nursery had higher levels of chronic health conditions and social disadvantage, consistent with the socioeconomic eligibility criteria for accessing free nursery places at ages 2 to 3 [65, 66].

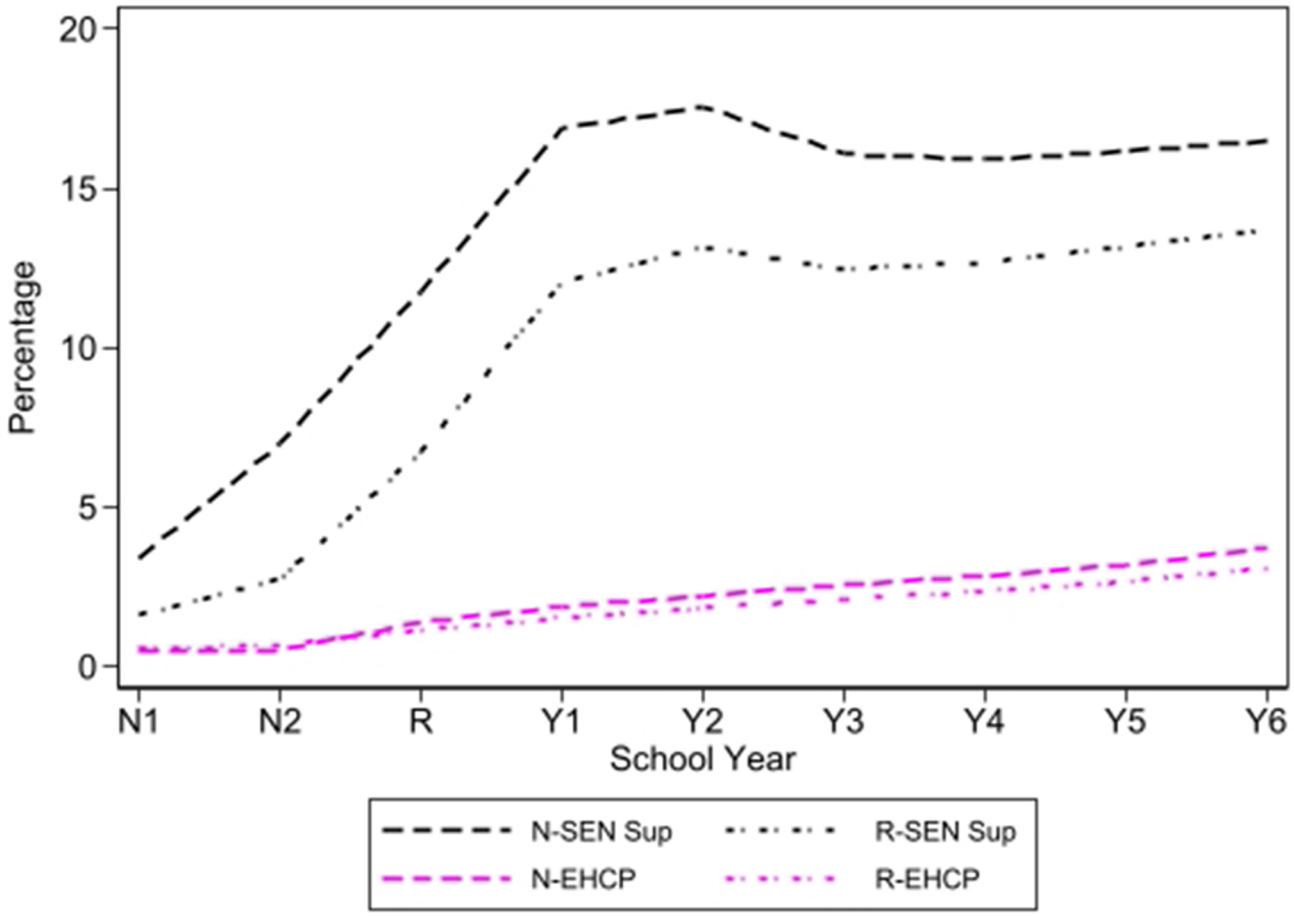
Using longitudinal data for the same cohort, we calculated the percentage of children assigned SEN Support or EHCP provision each year according to year of entry to state-funded education (including state-funded hours in private nursery provision) up to Year 6 (age 10/11). This percentage was highest among those entering state-provided education in Nursery and among the small group (0.4%) entering in Year 1, and lowest among those entering in Reception (Figure 4; note Year 1 entrants not shown to avoid small numbers). The proportion assigned SEN Support increased gradually, peaking in Year 2, before levelling off. In contrast, the proportion with an EHCP remained low (<5%) and rose only slowly throughout primary school [65]. For analyses of group characteristics of child who continued, started or stopped SEND provision between Year 1 and 6 see separate report [65].

We further explored the timing of SEND provision by analysing high-need children with cerebral palsy recorded in hospital admission records before entering state education (Cohort 8) [67]. We employed a staggered cohort design to account for differences in stage at entry into state education. At each stage at entry to education, and across combinations of sociodemographic variables (gender, neighbourhood deprivation and free school meal status), we estimated the average cumulative probability of any SEND or EHCP provision by year from Nursery to Year 6, using inverse probability weighted logistic regression.

Our analysis found no differences in EHCP probability by free school meal eligibility, but there was evidence of delayed EHCP provision for those living in the poorest neighbourhoods [67].

Time period is another factor influencing SEND provision. We assessed whether the Children and Families Act (2014) [2], enacted through the SEND Code of Practice (2015) [3], was associated with measurable changes in provision in Year 1 (Cohort 6, born 2003-14; Figure 5) [56]. Between academic years 2009/10 and 2018/19, the prevalence of SEND provision declined steadily among children with major congenital anomalies and their unaffected peers. Among unaffected children, the proportion recorded to have received any form of SEND provision in Year 1 fell by 4.2% after 2014, and by 4.8% for those with congenital anomalies [56].

Figure 4: School year percentage of children assigned SEN Support or EHCP provision during state-funded hours in Nursery or state Primary school (up to Year 6) according to stage at entry to state-provided education; Cohort 7 (born 2006/7 to 2007/8)



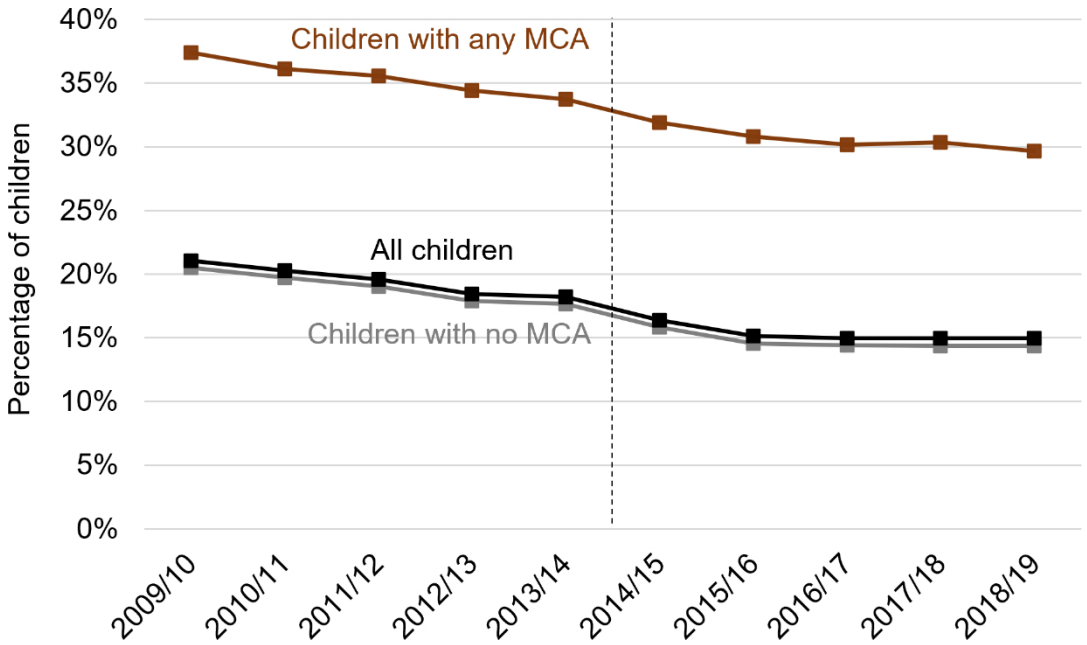

N-SEN Sup: Percentage of children assigned to SEN Support in each academic year among those who entered state-provided education in Nursery; R-SEN Sup: Percentage of children assigned to SEN Support in each academic year among those who entered state education in Reception; N-EHCP: Percentage of children assigned to EHCP in each academic year among those who entered state-provided education in Nursery; R- EHCP: Percentage of children assigned to EHCP in each academic year among those who entered state education in Reception.
The percentage of children in each academic year who were assigned SEN Support or EHCP are shown by stage at entry into state-provided education. N-SEN Sup and N-EHCP refer to children entering state-provided education in Nursery and R-SEN Sup and R-EHCP refer to those entering in Reception class. The small proportion (0.4%) entering in Year 1 is not shown. As SEND provision during state-funded hours in a private or voluntary nursery is included, children entering state-provided education in Reception can have SEND provision earlier [65].

There was no observable step change following the 2014 SEND reforms, thereby limiting the potential to exploit the legislative change as an instrumental variable in a natural experiment evaluating the impact of SEND provision [32].

**Where?**

Schools and LAs make decisions about SEND provision [3], but how schools are governed has changed considerably since 2007, with autonomous academy schools becoming more prevalent [68]. We assessed whether the type of school governance in Year 1 influenced SEND provision in the same year by analysing the experience of Cohort 7. School governance affects admissions policies, teaching about faith, and staff employment (Appendix 1, Table A1, Section 2). A shift to more autonomous schools, not controlled by the LA, has been progressing since 2007 [68]. We plotted the observed probabilities for any SEND, SEN Support or EHCP provision by school type. We then estimated equalised probabilities by controlling for (and then averaging over): the stage at entry to state education (Nursery, Reception, or Year 1), chronic health conditions, preterm birth, social disadvantage, demographic factors prior to stage at education entry and the EYFSP developmental score at age 5 [65]. We found substantial variation in the probability of SEN Support or EHCP provision in Year 1 across these different types of school governance [65]. Voluntary aided and voluntary controlled schools – typically religious schools – had the lowest rates of SEN Support and EHCP provision and academy sponsor-led and community schools had the highest rates (Figure 6). Variation diminished

Figure 5: Percentage of children assigned to any SEND provision in Year 1, by academic year and major congenital anomaly (MCA) status; Cohort 5 (born 2003-14)




MCA: major congenital anomalies; Black line: percentages for all children; Grey line: percentages for children without MCA; Brown line: percentages for children with MCA.

after equalising populations according to child-level differences in health characteristics, sociodemographic, stage at entry, and expected levels for the EYFSP assessment at age 5, but voluntary and academy sponsor-led schools had a lower probability of EHCP provision than community schools [65].

In separate analyses, we also assessed whether the LA of residence, which is responsible for funding and assigning EHCPs, influenced the probability of a child being assigned SEND provision using three subgroups of children from the extended whole cohort of children born in 2003 to 2014 (Cohort 6) [69]. Subgroups were defined by gestational age groups expected to have diminishing need for SEND provision: late preterm (34–36 weeks), early term (37–38 weeks), and full term (39–41 weeks). We quantified variation between LAs in the probability of receiving SEN Support, EHCP or any SEND provision in Year 1, by estimating the intraclass correlation coefficient (ICC) at each stage of multilevel models that controlled for child level health, social and demographic factors, EYFSP score age 5, school type (mainstream or special) and school governance [69]. After adjusting for child-level variables, only a small proportion of the variation was attributable to differences between LAs: it ranged from 2.0% for SEN Support (vs none) to 5.8 percent for EHCPs (vs SEN Support) across gestational age subgroups. Including LA income deprivation in the model reduced the variance in EHCP provision by up to 24 percent [69].

See key findings, Table 3.

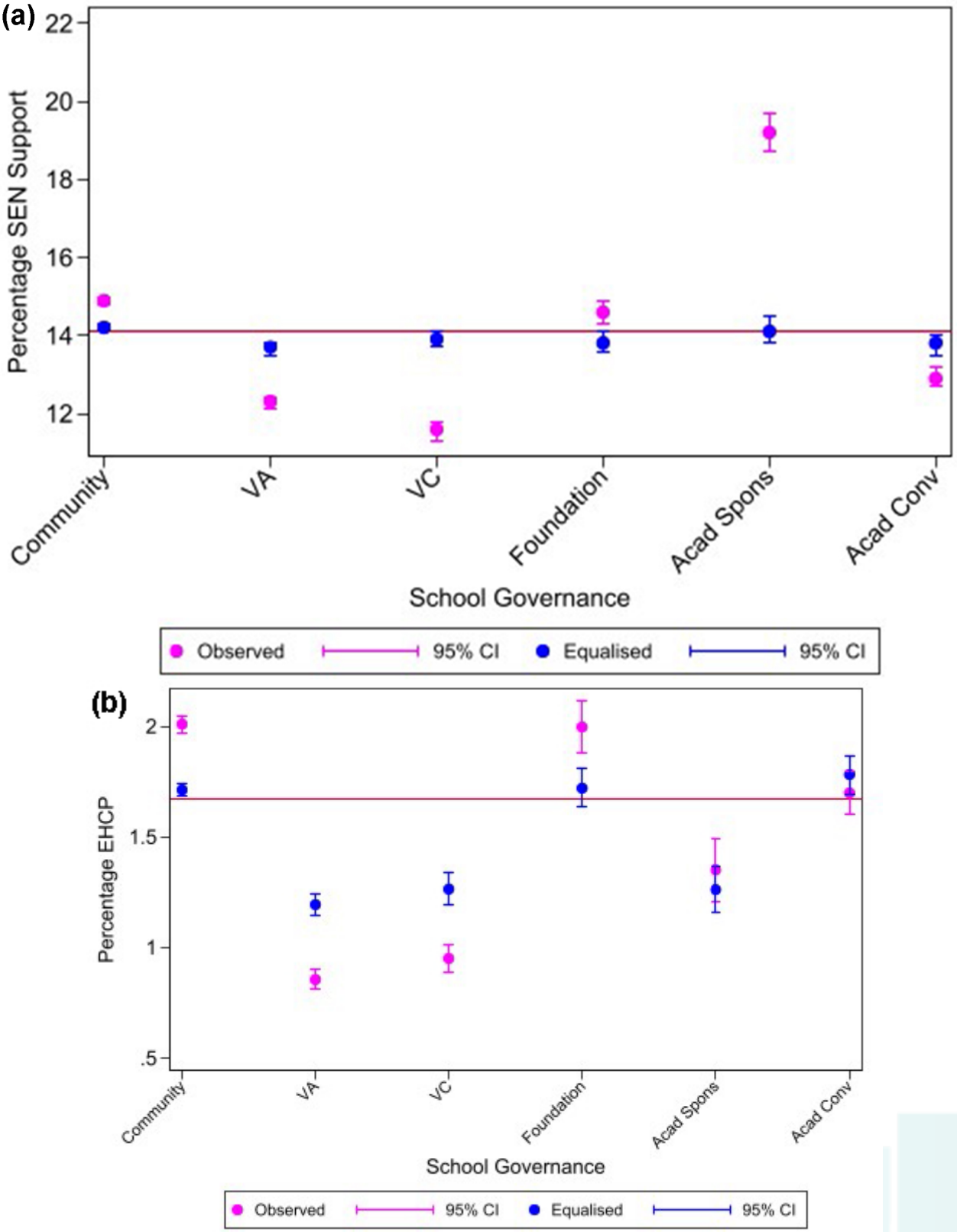
## Question 3: What is the impact of SEND provision on health and education outcomes?

We planned to use two quantitative approaches to evaluate the impact of SEND provision on health and education, i.e. to perform causal analysis. Both approaches are within the natural experimental framework [32]. The first approach involved assessing whether observed changes in policy, or differences in practices between schools or local authorities, introduced sufficient exogenous variation to enable the use of instrumental variable methods for the estimation of the impact of the new policies (see Appendix 1, Table A1 Section 3 for definitions). These methods can account for unmeasured confounding [32]. The second approach used the target trial emulation (TTE) framework to define causal questions that could replicate an ideal RCT with observational data [70]. The framework requires defining the causal contrasts of interest, the exposure (SEND provision), the relevant outcomes and confounders. Principled methods to deal with measured confounding, such as propensity score-based and g-methods are then adopted (under the additional assumptions of no interference, consistency and positivity). By making all elements of the causal question explicit, the TTE framework helps to minimise biases, for example, due to misalignment of study entry, eligibility and exposure assessment, or to incorrect assignment of later exposure status to an earlier period [71].

Our analyses for question 2 did not reveal any suitable instrumental variables to support the first approach. We therefore evaluated the impact of SEND provision using the TTE framework. We focussed on two sub-phenotypes of children: those with cleft lip with palate and those with cerebral palsy (Cohorts 9 and 10) [72, 73].

We chose cleft lip and/or palate as a phenotype likely to reflect mild to moderate need for SEND provision, because average differences in education and health outcomes between affected children and peers are small (Cohort 9) [72]. The cerebral palsy phenotype was chosen to proxy high need for EHCP provision using specific codes for cerebral palsy (Cohort 10) [73]. For each cohort, we iteratively refined the phenotype to increase similarity in need by excluding children

Figure 6: Observed and equalised* probability of (a) SEN Support and (b) EHCP provision by school governance (Cohort 7, born 2006-08)




SEN: Special education needs; EHCP: Education and Health Care Plan; VA: Voluntary aided; VC: Voluntary Controlled; Acad Spons: Academy Sponsored; Acad Conv: Academy Converter; CI: confidence interval.

The pink dots (with respective 95% confidence intervals) represent the observed probabilities for SEN Support (in part (a)) and EHCP (in part (b)) provision by school type; The blue dots (with respective 95% confidence intervals) represent the estimated equalised probabilities of, respectively, SEN Support and EHCP. These were obtained by fitting logistic regression models for SEN Support and EHCP that included: the stage at entry to state education (Nursery, Reception, or Year 1), chronic health conditions, preterm birth, social disadvantage, demographic factors prior to stage at education entry and the EYFSP score at age 5. The predictions from these models were then averaged over these features to obtained what we call 'equalised' probabilities, i.e. probabilities that would be observed if all schools had the same pupil characteristics (Appendix 4,paper 15) [69].

Table 2: Summary of findings of causal analyses to estimate the impact of SEND provision on health and education outcomes (Question 3; cohorts 9, 10) [72, 73]

| Phenotype and compared interventions in Year 1 | Unplanned admissions Year 2–Year 6 | Unauthorised absences Year 2–Year 6 | KS1 Year 2 | KS2 Year 6 |
|---|---|---|---|---|
| **Cleft lip and/or palate** (Cohort 10) | | | | |
| SEND Supp vs No Support in Year 1 (Ref) | No difference | Better in SEN Supp | Worse in SEN Supp | Worse in SEN Supp |
| **Cerebral palsy** (Cohort 9) | | | | |
| SEND Supp vs No Support in Year 1 (Ref) | Worse in SEN Supp | Better in SEN Supp | Worse in SEN Supp | No difference |
| EHCP vs SEND Support in Year 1 (Ref) | Worse in EHCP | Better in EHCP | No difference | Worse in EHCP |

EHCP: Education and health care plan; SEND: special educational needs and disabilities; SEN Supp : special educational needs Support; KS1: Key Stage 1; KS2: Key Stage 2 ; Ref: reference category.

with anomalies affecting other body systems. Outcomes were unplanned hospital admissions, unauthorised school absence in Years 2-6 and attainment in mathematics in Year 2 (age 6/7) and Year 6 (age 11).

We estimated the impact of SEN Support in Year 1 versus none for both phenotypes, and EHCP versus SEN Support in Year 1 (for cerebral palsy) on unplanned admissions, unauthorised absences and key stage test scores through primary school, Other comparisons were not possible because of lack of positivity [72, 73].

We found no evidence that SEN Support in Year 1 compared with none improved rates of unplanned hospital admissions or educational attainment in either the cerebral palsy or the cleft lip and/or palate phenotype subgroups. Findings were similar for EHCP vs SEN Support for children with cerebral palsy, except for reduced unauthorised absences (Table 2) [72, 73]. There was evidence that SEN Support compared to none reduced the rate of unauthorised absences for both phenotype groups (Table 2).

The findings of improved and worse outcomes in Table 2 should be interpreted with caution given the likely impact of residual confounding arising from the coarseness of the measures available in ECHILD. Furthermore, our choice of outcomes was limited by the accuracy and relevance of data available. For example, absences may be less likely recorded as unauthorised for children with an EHCP. Also, other outcomes relevant to learning or socio-emotional skills may not be captured in ECHILD [72, 73].

See key findings, Table 3.

## Question 4: What do service experiences and policies tell us about the process and delivery of SEND provision?

We conducted ten mixed methods sub studies to understand experiences of the SEND process from the perspectives of young people and parent-carers using the service and from professionals contributing to SEND provision in some way [11]. We examined three core stages of the SEND process: noticing the need, SEND assessment, and implementation of provision. We explored outcomes of these processes for the child and family, and wider influences such as service capability and policies (Figure 7). The mixed methods sub studies included qualitative studies (interviews and focus groups), online surveys (with children, young people, parents/carers, and professionals) and document reviews of Ombudsman complaints, Ofsted/CQC inspection reports, Local Offer (LO) websites and grey and peer-reviewed literature on variation in SEND processes and provision at LA and multi-academy trust levels (Appendix 1, Table A1, Section 5). Appendix 5 summarises methods and key findings from each of the 10 sub-studies mapped to stages of the SEND process (identification, assessment, received provision), outcomes, local capability and policy.

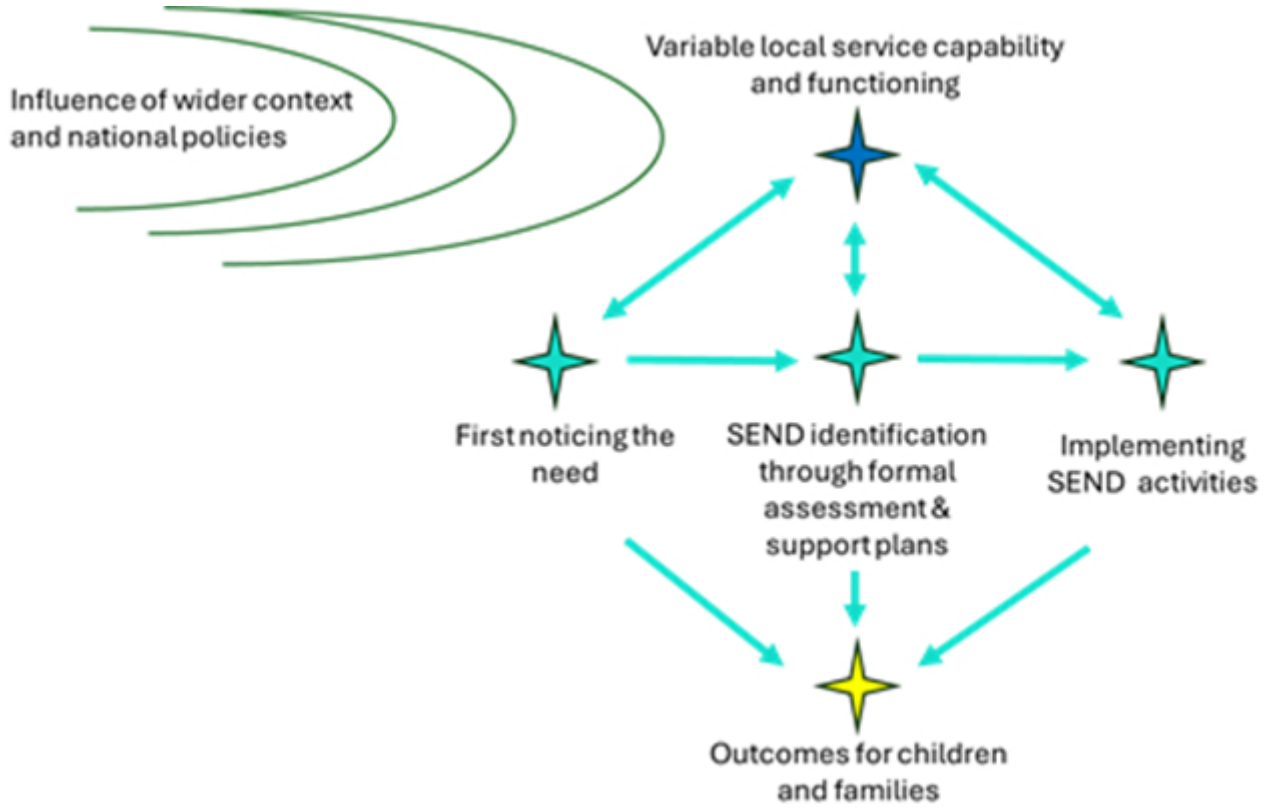
### Initial identification

In qualitative studies, professionals reported increasing numbers and complexity of the need for SEND provision, linked to worsening poverty and in some settings, better identification by experienced Special Educational Needs Coordinators (SENCOs; Appendix 4, paper 26) [74, 80]. Parent-carers reported that quiet children, and autistic girls were frequently under-identified [74]. Online surveys found that 25% of children had been identified in pre-school and 47% by Key Stage 1. Parents reported negative experiences of identification, inadequate professional training, long waits, and limited specialist availability [75, 76]. While most professionals felt confident in identification, they mostly agreed that interagency communication was weak [77]. Document reviews revealed variation by multi-academy trust (MAT), SENCO level of experience, and LA [80]. Many Local Offer (LO) websites lacked clear, accessible criteria and process information [78].

### Assessment and planning

EHCP processes were described in qualitative studies involving professionals as inefficient, due to poor interagency

Figure 7: Experiences of the SEND process, outcomes, and wider influences on local service capability to deliver services




working, information sharing systems, and a lack of shared understanding of SEND provision and processes (Appendix 4, paper 26). Parents reported that high intervention thresholds and referral bounce-back harmed relations with families and left children unsupported, sometimes for years [74]. Surveys found fewer than one-quarter of parents reported adequate information at assessment; only half of children felt involved in decisions [75, 76]. Less than half of professionals reported that parents unable to advocate were adequately supported through the SEND process [77]. Document reviews highlighted weakened EHCP quality due to inconsistent application of Children and Families Act (2014) legislation, varying criteria for some SEND types, funding-driven allocation, poor co-production and involvement of children, poorly defined outcomes, and incomplete LO website eligibility criteria (Appendix 4, paper 26) [78, 80]. Poor quality EHCP processes and provision were common reasons for LAs failing inspections(Appendix 4, paper 22).

### SEND provision

In the qualitative studies, we heard frequent reports of delayed and inappropriate SEND provision, harming children's education and mental health. Tailored support depended on good SENCO training. Parent-carers acted as primary advocates but were excluded from LA decision-making panels. Appeals improved provision but were slow and costly; annual reviews were uncommon (Appendix 4, paper 26) [74]. Surveys found 75% of children wanted earlier support; only half reported inclusion in class that was similar to peers. Only one-third of parents said provision matched plans, and 41% said plans matched needs [75, 78]. Only 45% of professionals rated SEND provision as positive: their level of confidence was mixed in being able to deliver SEND provision or having the capacity to support families [77]. Document reviews indicated that LAs were frequently under-resourced for needs-led delivery [80].

### Outcomes

Young people and parent-carers commented in qualitative studies that timely, tailored provision improved academic engagement, anxiety management, and independence [74, 79]. Challenging unmet needs took a toll on parent-carer mental health and finances. Professionals sometimes set unduly low aspirations [74]. Transitions required careful management, and reliance on parental advocacy reinforced inequities (Appendix 4, paper 26) [74]. In surveys, only half of parents reported that EHCPs included future goals; only one-third found these appropriately ambitious [75, 78]. Document reviews associated poor provision with dissatisfaction, complaints, and disproportionate exclusions (Appendix 4, paper 28) [74, 78, 80].

### Local service capability

Qualitative studies indicated capacity constraints due to workforce shortages, insufficiently trained staff, complex caseloads, funding deficits, inconsistent eligibility thresholds, and limited specialist availability. High-quality information systems improved interagency working but were rare (Appendix 4, paper 26) [74]. Surveys found low awareness of what SEND provision was available locally (the LO). High parent-carer dissatisfaction with LA assessment processes was reflected by 38% of parents reporting paying for private

assessments [75, 78]. Document reviews confirmed variation in local capacity, leadership, funding, EHCP rates, consistency of processes and interagency working [80]. Nationally, there were increasing complaints to the Local Government and Social Care Ombudsman (LGSCO) in an increasing number of LAs (Appendix 4, paper 28).

#### National policy context

Qualitative studies found that a narrow curriculum, exam-focused assessment, academisation, rigid attendance policies, and specialist shortages undermined inclusion and set some children up for failure (Appendix 4, paper 26) [74, 79]. Educators were increasingly absorbed in mental health roles, reducing capacity for prevention (Appendix 4, paper 26). Professionals reported that insufficient funding and training reduced service functioning and capacity (Appendix 4, paper 26) [77]. Document reviews found that professionals wanted nationally standardised processes and guidelines to improve quality. National policies on academisation reduced oversight and accountability for poor school practices on SEND provision. Some reports commented that the SEND code of practice led to under-recording of need, reduced the supply of specialist teachers and did not ensure LA compliance with legal requirements on the LO [78, 80].

See key findings, Table 3.

# Discussion

## Variation in SEND provision

Nearly one-third (30%) of children who entered primary school were assigned SEND provision by age 11 in 2014-19. SEND provision was strongly linked to health characteristics such as having a chronic health condition, including neurodisability or a congenital anomaly, or being born too early. However, these characteristics alone were not sensitive indicators of SEND provision. Other factors, such as being male, facing social disadvantage, and a low developmental score at age 5, were also important.

When children were assigned SEND provision was complex. Children with social disadvantage or disability, which is linked to eligibility for state-provided nursery at age 2-3, had higher rates of SEN Support and EHCP provision throughout primary school than their peers. Despite this increased provision, many did not start SEND provision until Year 1 or 2 (age 5–7), possibly due to delayed recognition, lack of school capacity, or changing need as education became more complex. However, in analyses of children with cerebral palsy, we found that those entering state education in Nursery and living in the 20% most income-deprived neighbourhoods were assigned EHCPs later on average than those from less deprived neighbourhoods [67].

Which type of school children attended was associated with their chances of SEND provision. Children attending voluntary, religious schools and academy sponsor-led schools were less likely to be assigned an EHCP compared with community, foundation and academy converter schools [65].

Findings from ten mixed methods studies highlighted variability in services. Some children and families reported meaningful benefits from provision, however, interactions with services, delays and inadequately tailored interventions frequently included negative experiences, some experiencing long term harm. Qualitative studies and surveys revealed unmet need and delays in identification of need, assessment, planning and provision, that particularly affected disadvantaged children who did not have parent-carers who could advocate for them. Parent-carer, child and professional perspectives and document reviews reflected services that lacked capacity, training and specialist expertise. These findings also highlighted a system that interacted poorly with other weakened systems (such as Child and Adolescent Mental Health Services) and lacked national guidance and accountability. These problems were compounded by underfunding, academisation, and a narrow curriculum that was perceived to undermine inclusion of children's diverse abilities.

## Impact of SEND provision

We found weak evidence that SEND provision in Year 1 (age 5/6) reduced rates of unauthorised absences, but no evidence for reductions in hospital admissions or improved attainment during primary school. These equivocal results are consistent with 49 natural experiment studies worldwide that evaluated SEND provision as implemented in routine practice (see introduction) [22, 23, 26–30].

These quantitative findings were complemented by qualitative findings in the HOPE study from parent-carers and children using SEND services and professionals. Their reports indicated that timely, tailored provision improved academic engagement, anxiety, and independence for children. However, the stresses of the SEND process, including inappropriate or inadequate provision, were experienced as harmful by children and their families.

## Strengths and limitations

Strengths of the HOPE study included exploration of the evaluability of SEND provision using different approaches to causal analyses using rich, longitudinal health and education data for all children in state-funded primary education in England captured in the ECHILD database. The value of combining mixed methods with quantitative methods for policy evaluation has been emphasised by Craig et al [32]. In the HOPE study, mixed methods and stakeholder engagement, alongside the quantitative analyses, were critical for understanding variation in the adequacy of SEND processes and the many elements that were not measured in administrative data.

Limitations centred on a data science problem: inadequate measures of the need for SEND and other confounders, limited information on the nature of the intervention, and insensitive or insufficiently relevant outcomes that might not be measurably changed by SEND provision. A further limitation was that we found no instrumental variables to use in natural experiment designs that address unmeasured confounding, despite major changes in national SEND policy and types of school over the past two decades. These limitations undermined the evaluability of the impact of SEND provision on health and education using quantitative analyses of ECHILD.

Table 3: Key findings from the HOPE[1] study

1. **Which health conditions (phenotypes) are associated with outcomes that might be improved by SEND[2] provision?**
   - Children with neurodisability, congenital anomalies, or preterm birth had more unplanned hospital admissions and more frequent school absences and lower attainment at age 7 and 11 compared to unaffected peers.
   - These outcomes were on average worse for children with neurodisability than for children with congenital anomalies or those born preterm.
   - Outcomes varied substantially between specific condition subgroups within each phenotype, and by week of gestational age at birth.

2. **What factors influence who is assigned SEND provision, and when and where this occurs?**

   ***a) Who is assigned SEND provision?***
   - Children with greater health needs, boys, summer-born pupils, and those from disadvantaged backgrounds were more likely to receive SEN[3] Support or an EHCP[4].
   - Rates of SEND provision were highest among children with neurodisabilities but hospital recorded conditions were inadequate proxies for the need for SEND provision.

   ***b) When is SEND provision assigned?***
   - The probability of being assigned SEN Support or an EHCP increased only gradually from Nursery onwards, peaking in Year 2 for SEN Support and in Year 6 for EHCP
   - Children who started in state Nursery were more likely to receive SEN Support or an EHCP throughout primary school than those starting in Reception.
   - Among children with cerebral palsy, 95% received SEN Support and 72% had an EHCP by the end of primary school.
   - SEND provision in Year 1 declined gradually from 2009/10 to 2018/19 with no appreciable step change when SEND reforms were introduced.

   ***c) Where is SEND provision assigned?***
   - Type of school governance was associated with SEND provision. Voluntary and academy sponsor-led schools had lower probability of EHCP provision than community schools after accounting for pupil characteristics.
   - Variation across LAs[5] was minimal and mostly explained by child characteristics and area-level deprivation.

3. **What is the impact of SEND provision on health and education outcomes?**
   - No evidence was found that Year 1 SEND provision reduced hospitalisations or improved attainment.
   - SEN Support was associated with reduced unauthorised absences compared with no support for cerebral palsy and cleft lip and palate, with additional reductions for EHCP vs SEN Support in cerebral palsy.
   - As not all indicators of need are measured, unmeasured confounding may affect both null and beneficial effects of SEND provision.

4. **What do service experiences and policies tell us about the process and delivery of SEND provision?**
   - Delays, inconsistent identification, and inequitable access to assessments were widespread, driven by workforce shortages, weak interagency coordination, variable LA practices, and increasing numbers of children with identified needs. EHCP processes were often inefficient, with limited parent and child involvement and poor communication.
   - SEND provision was frequently delayed, poorly matched to needs, or lacking in aspiration. It relied heavily on parental awareness of services, advocacy and SENCO[6] expertise. Timely, tailored support improved engagement and wellbeing, while inadequate provision harmed learning and mental health of children and other family members.
   - Funding cuts, workforce pressures, and academisation led to variation in service quality and accountability. A narrow national curriculum assessed by exams was partly driving the increase in additional support needs, as well as limiting the chances for some SEND learners to succeed.
   - Professionals called for clearer national standards, standardisation of key documents, stronger collaboration, and better resourcing to ensure equitable, effective provision.

**1.** HOPE Study: Health Outcomes for Young People Throughout Education; **2.** SEND: Special Educational Needs and Disabilities; **3.** SEN: Special Educational Needs; **4.** EHCP: Education and Health Care Plan; **5.** Local Authority; **6.** SENCO: Special educational needs coordinator.

## Challenges and opportunities in using administrative data

Our findings reflect challenges that are relevant to other jurisdictions that use administrative data to evaluate SEND provision. One lesson from the HOPE study is that health phenotypes as recorded in hospital data do not adequately proxy need for SEND provision. Linked hospital and education data lack direct measures of function, disease, severity or complexity of need, and social and behavioural factors linked to high need for SEND provision and worse outcomes [81].

Secondly, SEND provision recorded in ECHILD reflects assignment to the SEND process but not what activities or support were received, at what intensity and when. Young people and parent-carers reported frequent delays in receiving support, watered-down activities or activities the child did not tolerate, due to lack of capacity, skills or ability of staff to adapt activities to the child.

Third, the outcomes measurable in ECHILD - hospital admissions, attainment test results and school absences - are relatively insensitive to positive changes reported in response to SEND provision by parent-carers and young people. They mentioned feeling happier, less anxious or distressed, improved sense of self, behaviour and mental health, and being able to attend school, participate, learn and socialise. Impacts on parent wellbeing were also mentioned, while reduced hospital contacts for the child were not.

Data linkage to relevant information from administrative, cohort, survey, trial or audit data on need for, and content of, SEND provision, and on relevant outcomes, could mitigate these three challenges. Examples exist elsewhere. In Wales, researchers can access anonymised education data linked to primary care and hospital data, further enhanced with survey data on function and wellbeing in the HAPPEN cohort [82].

Fourth, the SEND process may have been harmful for some children and families. Our study spanned a period of national austerity, with cuts to education and related services, rising child poverty and need for SEND provision. These changes occurred in parallel to policy changes that incentivised academic attainment and reduced funding and accountability for progress among children with additional needs. Parents and practitioners reported erosion in the capacity or skills to deliver SEND provision of adequate quality. These problems created distrust between parents and school staff and undermined partnership working between staff, child and parent-carer.

Fifth, notwithstanding these limitations, the HOPE study illustrates the opportunities to inform policy makers, teachers, clinicians and families about children's trajectories through health and education and into adolescence. Descriptive analyses while being essential to design causal analyses, also provided important information on expected outcomes and variation and inequalities in SEND provision.

## Implications for policy

Achieving effective and equitable SEND provision is a policy challenge in many countries. SEND provision is an expensive and important service - £11 billion per year in England - with the potential to change the life opportunities of one-third of all children [8]. More effective and efficient services could improve experiences and outcomes for children and their families, limit escalating costs, and yield long-term benefits across public services as better supported, more independent and educated children with additional needs transition to adulthood. Broader policy changes are also needed beyond SEND provision, including broadening the academic curriculum to value and measure other forms of progress, including social and emotional skills. Beyond schools, better integration is needed between health and education services for children with additional health and social needs, and more support for parent-carers to reduce the toll on families.

Further reforms to SEND in the UK and elsewhere [8], need to be based on, and continue to generate, evidence of what works. Development of high quality linked data research infrastructure across education and other public services should be at the forefront of government's research areas of interest. Government should plan to integrate primary care data into the ECHILD database, to provide more granular data on the health determinants and consequences of education for children with additional health needs.

## Implications for research

Despite the hundreds of RCTs of targeted SEND interventions and, with this study, 49 natural experiment studies on the impact of SEND provision, uncertainty remains about what works for whom, in what contexts and how. Achieving effective SEND provision requires randomised trials of alternative approaches to SEND provision in situations where uncertainty exists and comparators are acceptable. For example, the HOPE study found that SEND is provided to few children in the general population in the preschool years (Nursery and Reception class). Although earlier implementation makes intuitive sense, and is provided for some disabilities such as visual impairment, there is limited evidence of benefit from contemporary nursery-based trials [83, 84]. A randomised, staggered trial should be considered to implement policy change in England and, at the same time, generate robust evidence on early versus deferred SEND provision in the early years [85].

Policy makers also need evidence on what good SEND provision and alternative practice options look like to develop meaningful evaluations of impact. Our mixed methods studies revealed a SEND service that few users experienced as being able to meet needs due to lack of funding, staff, skills, interagency support and trust from families [42]. Comparison of such a weakened system of SEND provision against education as usual is unlikely to advance policy.

More and better research is needed to guide development of effective and equitable SEND provision globally. International collaboration could accelerate delivery of research for example, sharing knowledge on administrative data linked across education, health and other sectors to enable parallel studies across diverse needs and contexts relevant to SEND provision. Surveys, cohort studies, and RCTs of SEND provision, or targeted components, in education or healthcare, could be conducted and linked into administrative data. Such linkages would minimise costs of data collection, and if conducted across jurisdictions, could improve comparability and give insights about differing impacts according to context. Sharing

of mixed methods approaches would improve understanding of services across jurisdictions.

International research collaboration is needed to build on the findings from the HOPE study through wider integration of natural experiment, randomised and mixed methods studies to improve the effectiveness of SEND provision. However, the challenges facing the HOPE study, are echoed by other population-based, service interventions, such as early home visiting for first-time, teenage mothers and perinatal mental health hubs [86, 87]. The recent framework on use of natural experimental designs [32], needs to be extended to consider how policy makers, funders, and researchers can introduce and document changes in policy and practice and efficiently enhance administrative data to enable robust evaluation of education, health and social interventions in populations.

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## Statement of conflicts of interest

Tamsin Ford's research group receives funding for research methods consultation from Place2Be, a third sector organisation that provides mental health and training to UK schools.

The other authors report no conflicts.

## Ethics statement

Existing research ethics approval has been granted for analyses of the ECHILD database version 1 for the purposes set out in the HOPE study (20/EE/0180). Permissions to use linked, de-identified data from HES and the NPD were granted by NHS England (DARS-NIC-381972-Q5F0V-v0.5) and the Department for Education (DR200604.02B). Patient consent was not required to use the de-identified data in this study.

## Data availability statement

The ECHILD database is made available for free for approved research based in the UK, via the ONS Secure Research Service. Enquiries to access the ECHILD database can be made by emailing ich.echild@ucl.ac.uk. Researchers will need to be approved and submit a successful application to the ECHILD Data Access Committee and ONS Research Accreditation Panel to access the data, with strict statistical disclosure controls of all outputs of analyses.

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# Appendix 1: Glossary of terms and abbreviations

Appendix 1: Glossary of common terms and variables used in the HOPE study (see separate reference list at end of supplementary materials)

| | |
|---|---|
| **Section 1. Phenotypes** | |
| **Neurodisability** | Chronic conditions involving impairment of the brain and/or neuromuscular system that result in functional limitations [1]. The list of conditions was informed by a scoping review of existing literature and refined through iterative clinical input. The full list conditions is available in the ECHILD phenotyping library [2]. |
| **Congenital anomalies** | Structural or functional birth defects that develop prenatally and serve as reliable early indicators of varying levels of need for SEND provision [3]. Subgroups were defined using the EUROCAT guide (version 1.5); we focused on a selection of major congenital anomalies categorised into 12 body system groups and 25 specific subgroups [3]. |
| **Chronic health conditions (CHC)** | Any health problem recorded in hospital admission data likely to require follow-up for more than 1 year, where follow-up could be repeated hospital admission, specialist follow-up through outpatient department visits, medication or use of support services [4]. We identified children with CHCs using the Hardelid code list and the full list of conditions is available in the ECHILD phenotyping library [2, 4]. |
| **Gestational age** | We stratified the whole population of children by week of gestational age at birth to assess the gradient in health and education outcomes across different levels of underlying need.<br>Due to small sample sizes, individuals born before 24 weeks or after 42 weeks of gestation were grouped together, as counts below 10 are suppressed or treated as confidential to protect individual privacy. |
| **Section 2. School governance and types of primary schools** | |
| **Inclusive education** | An approach to teaching that ensures all learners, regardless of ability, background, or need, have equal access to high-quality education, in line with UK laws such as the Equality Act 2010 and the SEND Code of Practice (2015) [5]. The core principles are valuing diversity as a strength, removing barriers to participation, fostering social cohesion, addressing attainment gaps, and preparing students with the skills and attitudes needed to thrive in a diverse society [6]. |
| **Special school** | Special primary schools in England serve pupils with a broad spectrum of special educational needs and disabilities (SEND; see section 5 in this glossary), particularly those with moderate to severe or complex disabilities. These schools provide tailored support and specialised learning environments designed to meet the needs of children who require more intensive or individualised interventions than those typically available in mainstream educational settings [7]. Almost all children in a special school have an education, health and care plan (EHCP) [8]. Special schools may be maintained by local authorities or operate as academies, including both sponsor-led and converter academies. They may be either faith-based or secular, and in exceptional cases, may operate as independent (private) schools [9].<br>Alternative provision (AP) refers to education arranged by local authorities for children of compulsory school age who cannot attend mainstream or special schools, often due to behavioural, medical, or other specific needs. The most common form of AP is the Pupil Referral Unit (PRU), which supports pupils who are excluded or otherwise unable to attend a school setting. Local authorities have a statutory duty to ensure suitable AP is provided in these circumstances [10]. |
| **Local Authority Maintained Schools** | |
| Local authority maintained schools are fully owned and operated by local authorities. They follow the national curriculum, are closely connected to their local communities, and may offer additional services such as childcare. Maintained schools can be named in an EHCP (previously termed Statement of SEN), following consultation with the local authority, and must comply with government regulations on admissions, exclusions, and SEND provision [11]. | |
| **Community school** | A local authority-maintained, secular school. The local authority manages admissions, staffing, and owns the buildings [11].<br>The proportion of community primary schools has reduced over time as Foundation and Academy Trust schools have increased from 2007 onwards [12]. |

Continued

Appendix 1: Continued

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|---|---|
| **Voluntary Aided school** | These schools are typically faith-based, though admissions are open to all applicants. They are jointly funded by the local authority and a supporting religious body, such as the Roman Catholic Church. The governing body employs staff, sets admissions policies, and contributes to building and maintenance costs. School premises are usually owned by a charitable foundation [11]. |
| **Voluntary Controlled school** | Similar to voluntary aided schools, these are mostly faith-based but are fully funded by the local authority. Whilst the local authority is responsible for admissions and employs school staff, it consults with the supporting body when setting the admissions policy. The land and buildings are typically owned by a charitable foundation [11] . |
| **Foundation school** | Funded by the local authority but are managed by their governing body, which acts as the admission authority. The governing body is responsible for employing staff and overseeing admissions. The land and buildings are owned either by the governing body or a charitable foundation [11]. |
| **Single Academy Trust (SAT) / Multi-Academy Trust (MAT)** | |
| A SAT is a standalone academy (sponsor-led or converter) with its own board of trustees, independent of local authority control and funded by the Department for Education. A MAT is a group of academies governed by a single board of trustees, sharing policies, leadership, and resources; MATs may include primary, secondary, and special schools. The HOPE study does not distinguish between schools under SATs or MATs [13, 14]. | |
| **Academy (Sponsor-led)** | State-funded school set up to replace underperforming schools. Overseen by an external sponsor (e.g., trust, charity). Operates independently from local authorities with freedom over curriculum, staffing, and budget [9, 14]. |
| **Academy (Converter)** | A higher-performing school that voluntarily converts to academy status. Funded directly by the Department for Education and has autonomy over operations and curriculum [9, 14]. |
| **Section 3. Methodology** | |
| **3.1 Quantitative methods** | |
| **Natural experimental evaluation** | Natural experiments are defined as events outside the control of researchers that divide populations into exposed and unexposed groups [15]. They pose a valuable opportunity to evaluate population health, health systems, and other interventions, including those that are, for practical or ethical reasons, not suitable for investigation using randomised controlled trials. A natural experimental evaluation uses differences in exposure generated by an event or process that arises independently of the outcome to identify, measure or understand the effects of that exposure [15, 16]. |
| **Instrumental variables** | A variable that is associated with exposure to an intervention but does not have a direct association, nor a shared cause, with the outcome of interest. It can be used to estimate the effect of exposure on an outcome even in the presence of unmeasured confounding. The formal definition of an instrumental variable is that: (1) it is associated with the outcome but (2) only through its association with the exposure (the 'exclusion restriction') and (3) it is unrelated to any other factors that cause the outcome [15]. |
| **Intraclass correlation coefficient (ICC)** | Measures the consistency or agreement of measurements within grouped data. It quantifies how much of the total variation is due to differences between groups versus within groups, indicating how similar members of the same group are compared to those in different groups [17]. |
| **Target trial emulation (TTE)** | A framework that applies the study design principles of randomised trials to observational studies that aim to estimate the causal effect of an intervention. This approach aims to reduce bias and strengthen causal validity in observational studies [18]. |
| **3.2 Qualitative methods** | |
| **Focus group discussions** | A focus group discussion (FGD) is a qualitative method where a moderator guides a selected group to discuss a topic in-depth. FGDs capture participants' attitudes, knowledge, and experiences through group interaction, revealing both shared understandings and diverse perspectives that might be missed in individual interviews [19]. |
| **Section 4. Datasets** | |
| **Education and Child Health Insights from Linked Data (ECHILD)** | A pseudonymised database which links administrative data from the National Pupil Database (NPD) and Hospital Episode Statistics (HES) [20]. The linkage rate between NPD and HES is high and improved with time (94-98%) [20, 21]. The version of ECHILD used in the HOPE study analyses contains data on approximately 14.7 million children and young people aged 0-24 in England who were born in NHS-funded hospitals between 1st September 1995 and 31st August 2020 [21]. |

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Appendix 1: Continued

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| **4.1 Health data** | |
| **Hospital Episode Statistics (HES)** | A national database that includes information on all National Health Service (NHS) acute hospital care and mortality data. Nearly all children born in England are born in NHS hospitals (97%), but HES excludes births in private hospitals or at home. Children can be followed from their birth admission through all subsequent NHS hospital contacts [21]. |
| **HES Admitted Patient Care (HES APC)** | Data that is collected on all admissions to NHS hospitals in England and is the main HES data module used in HOPE study analyses. A hospital admission includes any secondary care-based activity that requires a hospital bed, thus includes both emergency and planned admissions, day cases, births and associated deliveries [22]. |
| **International Classification of Diseases version 10 (ICD-10)** | A standardised medical classification system developed by the World Health Organisation [23]. In NHS hospitals, clinical coders use ICD-10 codes to record patient diagnoses based on care records or discharge summaries [22]. In HES APC data, diagnostic codes follow the ICD-10 system, which enabled us to identify cohorts of children with specific phenotypes of interest (e.g. chronic health conditions, including neurodisability or congenital anomalies) in analyses [21]. |
| **Office of Population Censuses and Surveys Classification of Interventions and Procedures version 4 (OPCS-4)** | A UK-specific statistical classification system used to code clinical procedures and interventions carried out in NHS hospitals [24]. OPCS-4 codes are recorded in HES APC data and were used in HOPE to identify groups of children with a phenotype of interest. |
| **4.2 Education data** | |
| **National Pupil Database (NPD)** | A record-level administrative data resource curated by the UK government's Department for Education that is used for funding purposes, school performance tables, policy making, and research [25]. NPD contains child-level and school-level data on all pupils in state schools in England. The primary module is the census, which has information on pupil characteristics and school enrolment. Other modules include alternative provision, exam attainment, absence and exclusions [25]. |
| **Early Years Census** | The Early Years Census (EYC) is an annual data collection by the Department for Education (DfE) in England. It captures information on children under 5 receiving free state-funded early education hours in various settings, including school-based nurseries, state-funded nurseries not based in schools and private, voluntary, or third sector nurseries delivering state-funded hours. Data is collected each January and includes information on children's age, gender, and ethnicity, as well as provider details [26]. |
| **Section 5. School variables** | |
| **Special Educational Needs (and Disabilities)** *Changes in language throughout the HOPE study. | The Special Educational Needs and Disability Act 2001 and the SEN Code of Practice (2001) define children with special educational needs as those who have a learning difficulty requiring special educational provision [27]. This includes difficulties in learning as well as disabilities. The Children and Families Act (2014) and the updated SEND Code of Practice use a similar definition but explicitly adopt the term SEND to encompass both special educational needs and disabilities [5, 28]. The SEND system is the formal framework used in England to identify children and young people who *'have a learning difficulty or disability which calls for special educational provision, has a significantly greater difficulty in learning than the majority of others of the same age, or has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age'* (See page 15, SEND code of practice) [5]. SEND provision refers to both types of support a child may receive under this system (SEN Support or EHCP).<br>. *In the HOPE study, we initially used the term 'SEN provision' to remain consistent with NPD. However, we shifted to 'SEND provision' to align with current policy language and to ensure that disabled children, especially those in mainstream education, are not overlooked or excluded [5]. Not all children with disability will have SEN; for example children with myopia (short sighted) technically have a disability, but provided they have glasses or contact lenses do not necessarily require SEN support. |
| **SEN Support** | A less intensive form of SEND provision received by most pupils identified as having special educational needs or disabilities. It is school-led and school-funded and may include short-term interventions such as speech and language therapy, or additional support with reading and learning [5]. |

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Appendix 1: Continued

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| **Education, Health and Care Plan (EHCP)** | A more intensive form of SEND provision for children and young people whose needs require legally enforceable support. EHCPs are assessed and partly delivered by the local authority and can remain in place until the age of 25 [5]. An EHCP can be delivered in both mainstream and special schools, depending on the child's needs. Funding is primarily provided by the local authority where the child or young person resides, with additional contributions from the educational setting they attend (which may be located in a different local authority area). EHCPs replaced Statements of SEN following the 2014 education reforms [29]. |
| **SEND Code of Practice** | Statutory guidance published in January 2015 for identifying, assessing, and supporting children with SEND in England, used by schools, local authorities, and health services [5]. |
| **Graduated approach** | A step-by-step method used in schools to identify and support children with SEND, involving assess, plan, do, and review cycles recommended in the SEND code of practice [30]. |
| **Local Offer** | Information published by each local authority about the education, health, and social care services available for children and young people aged 0–25 with SEND. It explains what support is expected to be available locally and how to access it. The Local Offer must be clear, regularly updated, developed with input from families, and include services both within and outside the local area. It also provides guidance on eligibility, decision making, support, and how to give feedback or make complaints [31]. |
| **Local Government & Social Care Ombudsman (LGSCO)** | An independent body that investigates complaints about local authorities, including issues related to education, social care, and SEND services. The Ombudsman investigates whether a council has acted unfairly or failed to follow proper procedures. The service is free, impartial, and usually used after all local complaint processes have been exhausted [32]. |
| **Early Years Childcare Providers** | Settings offering care and education for children aged 0–5, including nurseries, pre-schools, childminders, and school nursery classes. All 3- and 4-year-olds are entitled to 15 hours of free childcare (up to 30 hours for eligible families), which can be used at both state-funded and private providers. Private nurseries may charge for extras (e.g. meals, extended hours), even during funded hours, while state-funded nursery classes (in schools) typically do not [33, 34]. From 2014, children in families receiving welfare benefits, or with disability living allowance or an EHCP, were entitled to 15 free hours free nursery provision for 38 weeks a year from the age of 2. |
| **Academic school year** | Runs from 1st September to 31st August in England. Determines school year group placement and eligibility for assessments and services [35]. |
| **Compulsory schooling** | Children must start full-time education in primary school on 31 December, 31 March or 31 August following their fifth birthday - whichever comes first [36]. |
| **Stage at start of education** | The stage at education (see Question 2, paper 15, cohort 7) was defined as the year of starting state-funded education. This could be state-funded free hours in early years education, such as Nursery, or starting state-funded primary school (Reception class or Year 1). |
| **Early Years Foundation Stage Profile (EYFSP)** | A statutory assessment of children's development at the end of the Reception year (age 4/5). Teachers assess each child against 17 Early Learning Goals (ELGs) across 7 areas of learning (2012/13 onwards). For each ELG, children are judged as either meeting the expected level or 'emerging' (not yet meeting it). The Profile provides a reliable summary of development to support a smooth transition into Year 1 [37]. |
| **Good Level of Development (GLD)** | A child is defined as having achieved the GLD in the EYFSP if they have reached the expected level of development in the prime areas of learning (communication and language, physical development, and personal, social and emotional development) and the specific areas of literacy and mathematics [37]. EYFSP analysed in different forms. i) In Question 2 (Appendix 4, paper 15) EYFSP was standardised to a mean score and then categorised to a) not recorded, b) below the mean; c) mean or above. ii) in Question 1, Appendix 4, paper 7, it was analysed as a standardised mean score and also as a dichotomised variable: a) achieving a Good Level of Development; b) not achieving or not being assessed. Iii) In Question 1 Appendix 4 paper 5, dichotomised as a good level of development (as above in ii(b)). |
| **Key Stage 1 and 2 assessments (KS1, KS2)** | Key Stages are phases in the national curriculum in England, each covering specific school years with standardised subjects and assessments – also termed attainment. At the end of Year 2 (age 6–7), children take KS1 assessments in English (reading and writing), maths, and science. At the end of Year 6 (age 10–11), KS2 assessments cover English (reading, writing, grammar, punctuation and spelling), maths, and science [38]. KS1 assessments are marked locally in schools while the KS2 assessments are externally marked [39, 40]. Students who did not follow the National Curriculum (disapplied) or who were assessed according to alternative standards (P-scales), were considered as "not assessed" for our study. |

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Appendix 1: Continued

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| **Authorised absences** | The number of school sessions (half-days) a child misses in an academic year with the school's permission. These absences are reported by schools and may be due to illness, medical or dental appointments, religious observance, study leave, agreed family holidays, or other approved reasons [25, 41]. |
| **Health-related absences** | An authorised school absence recorded due to illness or medical/dental appointments, as classified in the NPD. Used as a health outcome measure in studies of children with neurodisability (Paper 18) [42]. |
| **Unauthorised absences** | The number of school sessions (half-days) a child misses in an academic year without permission from the school. This includes unexplained or unjustified absences such as truancy, unapproved holidays during term time, lateness, and absences where no reason has been provided [25, 41]. |
| **Persistent absence** | Refers to pupils who miss more than 10% of possible school sessions in an academic year, regardless of whether the absences are authorised or unauthorised [25, 41]. |
| **Section 6. Sociodemographic variables** | |
| **6.1 Developmental indicators** | |
| **Gender** | NPD variable based on the legal sex of the pupil as reported by the parent or carer. It is recorded as either 'male' or 'female' and does not capture gender identity [43]. |
| **Sex at birth** | Based on sex recorded during HES birth admission(male/female) in analyses for question 1, and from NPD for analyses used in questions 2 and 3. |
| **Month of birth** | Refers to the month in which a child is born, as recorded in the HES birth admission. In the context of education in England (where the academic year runs from September to August) birth month has been shown to influence both cognitive and non-cognitive skill development, particularly in primary school [44]. Children born in summer months (e.g., July or August) may be nearly a year younger than some of their classmates born in autumn (e.g., September or October), placing them at a developmental disadvantage early in their schooling [44]. Month of birth was adjusted for in analyses by regrouping into four categories: September–November, December–February, March–May, and June–August. |
| **6.2 Health characteristics** | |
| **Birth weight** | Birth weight (in grams) was obtained from Hospital Episode Statistics (HES) birth admission records and supplemented using linked maternal health records where available. It was grouped into four categories: <2500g, 2500–4000g, >4000g, and missing [45]. |
| **Gestational age** | Gestational age (in completed weeks) was obtained from Hospital Episode Statistics (HES) birth admission records. It was used both as a continuous, week-by-week variable and grouped into categories for stratified analyses: very preterm (24–31 weeks), moderately preterm (32–33 weeks), late preterm (34–36 weeks), early term (37–38 weeks), and full term (39–41 weeks) and missing [46]. |
| **Phenotypes** | See Section 1of this table. |
| **6.3 Racial-ethnic characteristics** | |
| **Ethnicity** | NPD variable recording mode of ethnicity across any School Census that the pupil was included in. Can be recorded in the NPD as any of these categories: Asian, Chinese, Black, Mixed, White, Any Other Ethnic Group, and Unclassified/Missing [43]. |
| **Primary language** | NPD variable indicating pupil's primary language group. Recorded to be English, Other than English – which is often labelled 'English as an alternative language' (EAL), and Unclassified/Missing [43]. |
| **6.4 Region/local government** | |
| **Local authority** | Local authorities (152 across England) are organisations that are officially responsible for a range of local services for individuals and businesses, including education, some health services and social services. Encompasses 24 county councils, 59 unitary authorities, 36 metropolitan district councils and 33 London boroughs [47]. |
| **Region of residence** | NPD variable taken from earliest recording in School Census (usually Reception or Year 1). Using the local authority of a pupil's recorded home address, we create groups corresponding to Government Office Region (GOR). North East, North West, Yorkshire and the Humber, East Midlands, West Midlands, East of England, London, South East, South West [43]. |

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Appendix 1: Continued

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| **6.5 Indicators of social disadvantage** | |
| **Maternal age at delivery** | Maternal age at delivery was obtained from the HES birth admission record. A 'young mother' was defined as being under 20 years old at delivery and used as an indicator of social disadvantage. In stratified analyses, maternal age was categorised into six groups: <20, 20–24, 25–29, 30–34, 35–39, and 40+ years [46]. |
| **Index of Multiple Deprivation (IMD)** | The Index of Multiple Deprivation (IMD) is the official measure of relative deprivation in England. It ranks small geographic areas called Lower-layer Super Output Areas (LSOAs) from most to least deprived based on a combination of factors such as income deprivation, employment deprivation, education and crime [48]. |
| **Income Deprivation Affecting Children Index (IDACI)** | The Income Deprivation Affecting Children Index (IDACI) is a measure of the proportion of children aged 0–15 living in income-deprived households within a local area in England. It is a sub-domain of the Index of Multiple Deprivation (IMD) and is used to assess levels of child poverty [49]. In ECHILD, the IDACI decile of each child's lower super output area of residence is linked to their pupil record. |
| **Free school meal eligibility (FSM)** | A measure indicating whether a child meets the criteria to receive free school meals based on family income and receipt of certain benefits. Families need to register to be indicated as eligible in the NPD, thus children may not be recorded as such if they do not sign up. FSM eligibility is often used as a proxy for socioeconomic disadvantage in education data [50]. |
| **6.6 Outcomes used in ECHILD analyses** | |
| **Planned admissions** | A planned admission is a hospital admission where the decision to admit has been made in advance and the patient is admitted at a later date. These are typically part of a planned course of treatment or care, rather than in response to an urgent clinical need. Planned admissions usually follow from an outpatient consultation or a previous hospital episode and are scheduled to take place after a waiting period. Planned admissions were determined using if the *admimeth* variable in HES was coded as 11, 12, 13, 81, 84, 89 [42, 51]. |
| **Unplanned admissions** | An unplanned admission refers to a hospital admission that occurs unexpectedly and without prior scheduling. These admissions typically arise from an urgent or emergency clinical need. Unplanned admissions were determined using *admimeth* codes: 21, 22, 23, 24, 25, 28, 2A, 2B, 2D. [42, 51]. |
| **Mortality** | The proportion of children in the cohort who died during the follow-up period, expressed relative to all live births in the cohort. Mortality is reported for two time windows:<br>i) Before school entry (from birth up to the start of Year 1);<br>ii) During primary school (from Year 1 to the end of Year 6). Used in Question 1, Paper 2. |
| **Attainment at KS1 and KS2** | See section 5 of table. |
| **Good Level of Development (GLD)** | See section 5 of table. |
| **Authorised absences/ unauthorised** | See section 5 of table. |
| **Total absences** | Total absences are counts of half day periods available in the school year. This can be reported as a proportion of total available sessions. Used in Questions 1, 3 (Papers 3, 16) |

Appendix 2: Abbreviations of commonly used terms in the HOPE study

| Abbreviation | Full term |
|---|---|
| ADHD | Attention-Deficit/Hyperactivity Disorder |
| AP | Alternative provision |
| CA | Congenital Anomalies |
| CAMHS | Child and Adolescent Mental Health Services |
| CFA | Children and Families Act |
| CHC | Chronic Health Condition |
| CLP | Cleft Lip/ Palate |
| CP | Cerebral Palsy |
| CQC | Care Quality Commission |
| CYP | Children and Young People |
| DfE | Department for Education |
| DHSC | Department for Health and Social Care |
| ECHILD | Education and Child Health Insights from Linked Data |
| EHCP | Education, Health and Care Plan |
| EYFSP | Early Years Foundation Stage Profile |
| FGD | Focus Group Discussion |
| FSM | Free School Meals |
| GA | Gestational Age |
| GLD | Good Level of Development |
| HES | Hospital Episode Statistics |
| HES A&E | Hospital Episode Statistics Accident & Emergency |
| HES APC | Hospital Episode Statistics Admitted Patient Care |
| HOPE | Health Outcomes of young People throughout Education |
| IDACI | Income Deprivation Affecting Children Index |
| ICC | Intraclass Correlation Coefficient |
| IMD | Index of Multiple Deprivation |
| IV | Instrumental Variable |
| KS | Key Stage |
| LA | Local Authority |
| LGSCO | Local Government and Social Care Ombudsman |
| LO | Local Offer |
| LSOA | Lower-layer Super Output Area |
| MAT | Multi-Academy Trust |
| N1 | Nursery 1 |
| N2 | Nursery 2 |
| NC | National Curriculum |
| ND | Neurodisability |
| NHS | National Health Service |
| NIHR | National Institute of Health and Care Research |
| NPD | National Pupil Database |
| ONS | Office for National Statistics |
| PMR | Pupil Matching Reference |
| PPI | Public and Professional Involvement |
| PRU | Pupil Referral Unit |
| PSC | Programme Steering Committee |
| RCT | Randomised Control Trial |
| SAT | Single Academy Trust |
| SEN | Special Educational Needs |
| SENCO | Special Educational Needs Coordinator |
| SEND | Special Educational Needs and Disability |
| SEND CoP | Special Educational Needs and Disability Code of Practice |
| TTE | Target Trial Emulation |
| VA | Voluntary Aided |
| VC | Voluntary Controlled |

# Appendix 2: Details of involvement of public, professional and government stakeholders.

## Public and Professional Involvement (PPI)

Public and professional involvement (PPI) was supported by the teams from Cambridge (Ford/ Saxton) working in collaboration with the team from Exeter (Logan/ Boddy). We consulted young people and parent-carers using SEND services and professionals with experience of delivering or commissioning services. Collectively, we refer to these groups as stakeholders. These consultations were separate from but informed the qualitative studies that involved stakeholders (young people, parent-carers and professionals) as participants in research. In a few cases, the same individuals were consulted as advisers and involved as participants in studies, or as peer interviewers.

1. **Involving young people and parent-carers – The HOPE Study**

### Independent Programme Steering Committee

Before the study began, we recruited two parent-carers (KE and JO) of children receiving SEND provision to be part of the independent Programme Steering Committee to shape the direction of the HOPE Study and provide strategic oversight of the study and its relevance to policy and practice.

### PPI advisory group members

At the beginning of the study, we began recruiting members to join three PPI advisory groups through our steering committee members, wider professional networks, and by advertising on social media and through SEND journals. Group membership remained open throughout the study and the current numbers per group are as follows:

1) children and young people with SEND (n = 14).

2) parents/carers of children with SEND (n = 34).

In addition to having our own PPI groups, we consulted young people and parent-carers from two external advisory groups. One group, called FLARE (standing for Friendship, Learning, Achieve, Reach and Empower), involved children and young people with disability. This group was commissioned by the Department for Education (DfE) and affiliated to the Council for Disabled Children. The other involved parent-carers of disabled children advising the Peninsula Children's Research Unit (PenCRU) and was affiliated to the University of Exeter and facilitated by Kate Boddy.

### How PPI members were involved

The advisory groups were involved in several ways: online meetings, online drop-in sessions, and through the provision of written/emailed feedback. All PPI advisory members were reimbursed for their time in accordance with NIHR requirements. The PPI groups influenced The HOPE Study positively both to improve the quality of our research processes and tools, and to ensure the research itself was useful and relevant to service users. Below are three ways, with examples, of how the groups were involved and influenced the study:

1. **Ensuring questions asked in interviews and surveys were appropriate, relevant and likely to highlight factors influencing variation in SEND provision and outcomes**. For example, all PPI groups helped to develop our online survey. We received more than 200 question suggestions from the groups, and though we could not include all, we identified common issues around trust between families and professionals, and training standards for SEND professionals, which were included in the survey.

2. **Review of language in documents.** We asked PPI group members to review our tools (such as topic guides) and our participant information sheets and consent forms to ensure the language was appropriate and understandable.

3. **Contribution as observers of focus group discussions (FGD):** We trained six groups of Parent-carers to observe focus group discussions with SEND professionals, to help us interpret the resulting data. Three of these parent-carers were able to attend six focus groups and provided input on the interpretation of the findings. These three also provided critical feedback on the report of the focus groups and were included as co-authors.

*How the PPI groups added to our conclusions, beyond data collection*

Many of the perspectives form advisory group members were echoed in the mixed methods research findings. Key messages, over and above what the mixed methods told us were:

1. There needs to be a radical overhaul of the education system to enable sufficient flexibility to accommodate and meet everyone's needs. The ambition for most children with SEND provision to be educated in mainstream settings and to reach their full potential will not be realised without policy change away from the narrow focus on core academic subjects. SEND provision is delivered by teachers with inadequate SEND training and resources. The emphasis on using exams to assess children's learning is experienced as punitive by many children, particularly those with high levels of anxiety and who contend with sensory processing difficulties and sensory overload.

2. Young people with SEND who are at the point of leaving the education system, and for whom additional education needs will be lifelong encounter unfair barriers to employment and difficulties accessing adult health services due to differing thresholds for care in the post-16/post-18 period. The message from group members was that more attention needs to be paid to the 16-25 group with SEND to ensure they are supported and included in society.

3. The current SEND system is bringing many parents/carers to breaking point – and many have had to reduce

hours or give up work completely to manage paperwork demands. It is clear that parent/carer advocacy is a critical factor in being able to access SEND services – too much depends on them at the moment. Our group members were also keenly aware that they are the people who have the resources (time, energy, money) to engage with what the system requires of them (albeit at a cost). Many parents/carers do not have capacity to do this, which is likely to mean that their children will have needs that remain unmet, exacerbating inequalities between groups. This is not about 'sharp elbowed parents' unfairly taking resources from others, rather that elbows should not need to be sharp to ensure basic provision.

2. **Involvement of professionals**

### Independent Programme Steering Committee (PSC)

The PSC was chaired by an expert in social education and health research, Professor Chris Bonell. Other members were Dr Karen Horridge, a senior community paediatrician, Dr Jo Hutchinson, a researcher in SEND provision, and the two parent-carer members. The PSC met four times during the study and members were involved in additional discussions when their expertise was sought by the study team.

### Professional advisory group members

The team at Cambridge University recruited a wider stakeholder group of professionals ($n = 35$), mainly working in schools or health (e.g. therapists, psychologists) to deliver SEND provision, or in local authorities, social care or third sector SEND services.

## Consultation With Government Stakeholders

Teams at UCL and Cambridge both submitted evidence from The HOPE Study to the 2025 UK Government Education Committee enquiry 'Solving the SEND Crisis' [52]. We also held three meetings between March and July 2025, when we jointly presented and discussed key findings and implications with government stakeholders to inform our synthesis of key findings and implications for policy and research. The government stakeholders were : a) the Children's Commissioner's Office (an executive non-governmental body sponsored by the Department for Education (DfE); the Department of Education; and c) the Department of Health and Social Care (DHSC; UCL team only). These meetings were arranged via the NIHR Children and Families Policy Research Unit [53], (and the ECHILD partnership with government (DfE).

# Appendix 3: Derivation of cohorts used in analyses

Appendix 3: List of ECHILD-derived cohorts used in HOPE sub-studies grouped by analytical question (see Figure A1)

| Cohort Number | Population of Interest | Details | Papers* |
|---|---|---|---|
| **Q1: Which health conditions (phenotypes) are associated with outcomes that might be improved by SEND provision?** | | | |
| 1 | Neurodisability | 6 birth years (2003/4-2008/9)<br>No school linkage<br>N=3,580,225 | 2, 10 |
| 2 | Neurodisability | 6 birth years (2003/4-2008/9)<br>Y1 school entry<br>N=2,956,299 | 2 |
| 3 | Neurodisability, Congenital Anomalies | 5 birth years (2003/4-2007/8)<br>Reception school entry<br>N = 2,351,589 | 3, 5, 7 |
| 4** | Gestational age across whole population | 1 birth year (2004/5)<br>Reception school entry<br>N = 306,717 | 11 |
| **Q2: What factors influence who is assigned SEND provision, when and where?** | | | |
| 2 | Neurodisability | As above | 2 |
| 3 | Gestational age** | As above (used for Figure 3) | |
| 5 | Congenital Anomalies | 11 birth years (2003/4-2013/14)<br>Y1 school entry<br>N = 5,189,922 | 9 |
| 6 | Whole population (excluding births before 34 weeks of gestation) | 11 birth years (2003/4-2013/14)<br>Y1 school entry<br>N = 3,729,265 | 13, 14 |
| 7 | Whole population | 2 birth years (2006/7-2007/8)<br>Y1 school entry<br>N = 983,652 | 15 |
| 8 | Cerebral Palsy only*** | 10 birth years (2003/4-2012/13)<br>Nursery 1 entry<br>N = 5,669 | 12 |
| **Q3: What is the impact of SEND provision?** | | | |
| 9 | Cerebral Palsy only*** | 11 birth years (2003/4-2013/14)<br>Y1 school entry<br>N = 3,275 | 18 |
| 10 | Cleft Lip and/or Palate only*** | 11 birth years (2003/4-2013/14)<br>Y1 school entry<br>N = 6,601 | 16, 17 |

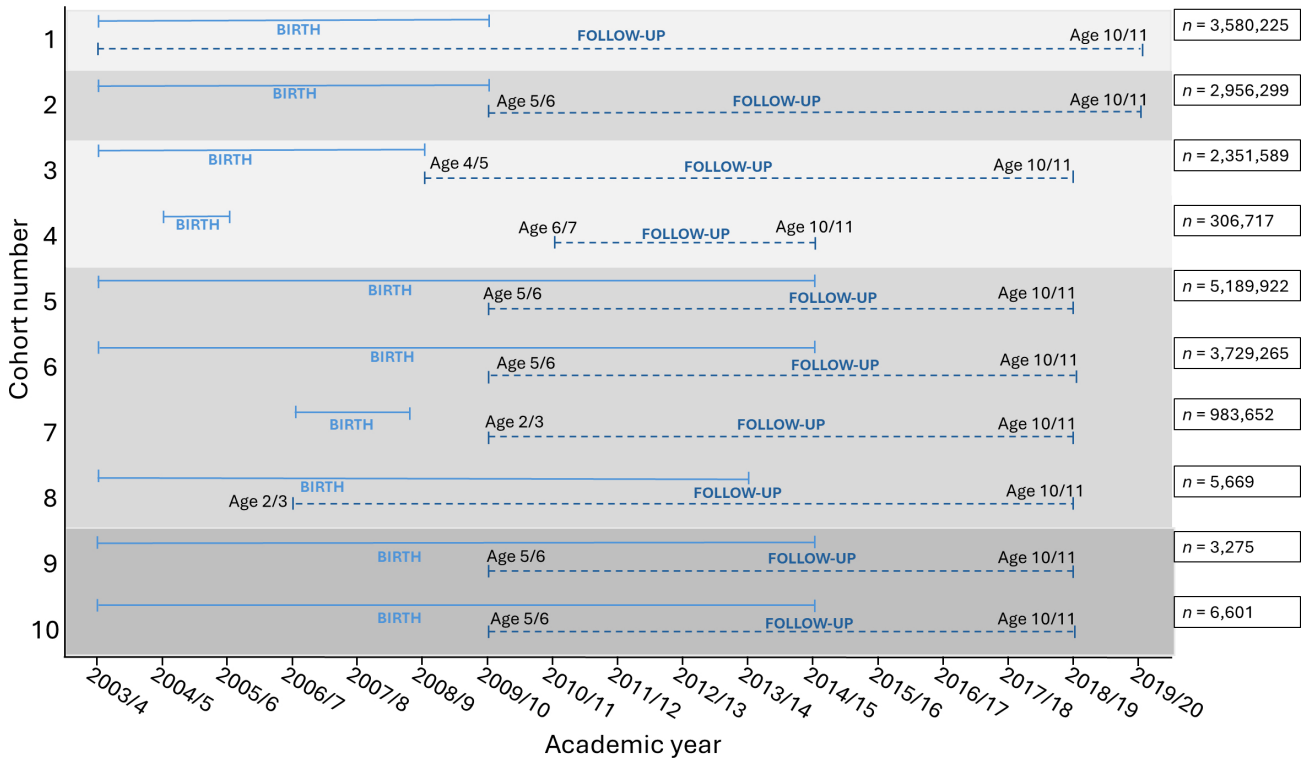
Y1: Year 1.

*Paper list can be found in Appendix 4.

**Data access for this cohort used in early work was restricted to one year.

***Cohorts 8, 9 and 10 are restricted to children with the phenotype only. All other cohorts include children with phenotype and unaffected peers.

Figure A1: Cohort diagram



# Appendix 4: List of HOPE sub-study publications.

| No. | Paper Name | Analysis cohort | Question (phenotype-colour coded) |
|---|---|---|---|
| **Research papers** | Zylbersztejn A, Lewis K, Nguyen V, et al. Evaluation of variation in special | N/A | All |
| 1 | educational needs provision and its impact on health and education using administrative records for England: umbrella protocol for a mixed-methods research programme. *BMJ Open*. 2023;13:e072531. Available from: https://doi.org/10.1136/bmjopen-2023-072531 | | Protocol |
| 2 | Zylbersztejn A, Rees P, D'Souza R, Logan S, Cant A, Gimeno L, et al. 2025;Phenotyping Neurodisability in Hospital Records in England: A National Birth Cohort Using Linked Administrative Data - Zylbersztejn - Paediatric and Perinatal Epidemiology - 2025 (Jul); https://onlinelibrary.wiley.com/doi/abs/10.1111/ppe.70052 | 1,2 | Q1 & Q2 |
| 3 | Gimeno L, Zylbersztejn A, Cant A, Gilbert R, Harron K. Hospital admissions and school absences among primary school children with and without neurodisability: Linked administrative data cohort study in England. 2025; Developmental Medicine and Child Neurology,2025 (Dec); https://doi.org/10.1111/dmcn.70128 | 3 | Q1 |
| 4 | Gimeno L, Zylbersztejn A, Cant A, Gilbert R, Harron K. Planned and unplanned hospital admissions and health-related school absence rates in children with neurodisability: Protocol for a population-based study using linked education and hospital data from England. [version 1; peer review: 1 approved, 3 approved with reservations]. *NIHR Open Res* 2024; 4:26. Available from: https://doi.org/10.3310/nihropenres.13558.1 | 3 | Q1 protocol |
| 5 | Cant A, Zylbersztejn A, Gimeno L, Nguyen V, Tan J, Gilbert R, et al. Educational attainment among primary school children with neurodisability: A population-based cohort study using linked education and health data from England [Internet]. 2025 Jun. [cited 2025 23];2025.06.12.25329491. Available from: https://www.medrxiv.org/content/10.1101/2025.06.12.25329491v1 Archives of Diseases in Childhood (in press). | 3 | Q1 |
| 6 | Cant A, Zylbersztejn A, Gimeno L, Nguyen V, Tan J, Gilbert R, et al. Primary school attainment outcomes in children with neurodisability: Protocol for a population-based cohort study using linked education and hospital data from England [version 1; peer review: 2 approved with reservations]. *NIHR Open Res* 2024, 4:28. Available from: https://doi.org/10.3310/nihropenres.13588.1 | 3 | Q1 protocol |
| 7 | Tan J, Cant A, Lewis KM, Nguyen V, Gimeno L, Zylbersztejn A, et al. Educational attainment of children with major congenital anomalies during primary school in England: a population cohort study using linked administrative data from ECHILD [Internet]. 2025 Jun. [cited 2025 24];2025.06.21.25329922. Available from: https://www.medrxiv.org/content/10.1101/2025.06.21.25329922v1 | 3 | Q1 Congenital anomalies |
| 8 | Tan J, Cant A, Lewis KM, Nguyen V, Gimeno L, Zylbersztejn A, et al. Educational outcomes of children with major congenital anomalies: Study protocol for a population-based cohort study using linked hospital and education data from England [version 1; peer review: 2 approved, 2 approved with reservations]. *NIHR Open Res* 2024, 4:68. Available from: https://doi.org/10.3310/nihropenres.13750.1 | 3 | Q1 protocol |
| 9 | Peppa M, Lewis KM, De Stavola B, Hardelid P, Gilbert R. School-recorded special educational needs provision in children with major congenital anomalies: A linked administrative records study of births in England, 2003-2013. *Int J Popul Data Sci* 10:2519. https://doi.org/10.23889/ijpds.v10i1.2519 | 5 | Q1, Q2 |
| 10 | Shumway J, Ellis J, Stephens A, De Stavola BL, Gilbert R, Zylbersztejn A. Hospital-recorded chronic health conditions in children with and without Down syndrome in England: a national cohort of births from 2003 to 2019. *Arch Dis Child* 2025 Mar.;110:221. https://doi.org/10.1136/archdischild-2024-327532 | 1 | Q1 |
| 11 | Libuy N, Gilbert R, Mc Grath-Lone L, Blackburn R, Etoori D, Harron K. Gestational age at birth, chronic conditions and school outcomes: a population-based data linkage study of children born in England. *International Journal of Epidemiology* 2023 Feb.;52:132–43. https://doi.org/10.1093/ije/dyac105 | 4 | Q2 Week of gestation at birth |
| 12 | Lewis KM, Nguyen VG, Ní Chobhthaigh S et al. Sociodemographic variation in cumulative probability of recorded special educational needs and disability provision during primary school in England: A staggered cohort study of children with cerebral palsy [version 1; peer review: awaiting peer review]. *NIHR Open Res* 2025, 5:61. https://doi.org/10.3310/nihropenres.14006.1 | 8 | Q2 |
| 13 | Kate Lewis, Vincent Nguyen, Ruth Gilbert, Bianca De Stavola, Lorraine Dearden. Local authority variation in school-recorded special educational needs provision in Year 1 among children born in England, 2003-2013. Eur J Pub Health (in press) | 7 | Q2 |
| 14 | Lewis K, Nguyen V, Zylbersztejn A, Gilbert R, De Stavola B, Dearden L. Local authority variation in primary school-recorded special educational needs provision among children with major congenital anomalies: A research protocol. *NIHR Open Res* 2023 Oct.;3:50. https://doi.org/10.3310/nihropenres.13466.1 | 5 | Q2 protocol |

Continued

| No. | Paper Name | Analysis cohort | Question (phenotype-colour coded) |
|---|---|---|---|
| 15 | Bianca L De Stavola,[1*] Kate M. Lewis,[1] Vincent G. Nguyen,[1] Andrea Aparicio Castro,[1] Lorraine Dearden,[2] Ruth Gilbert,[1] on behalf of the HOPE study team. Is there evidence of inequalities in the provision, level, and timing of SEND in English primary schools? Preprint Is there evidence of inequality in the provision, level, and timing of SEND provision in English primary schools? Preprint medRxiv 2025(Aug); https://doi.org/10.1101/2025.08.27.25334554. British Education Research Journal (under review) | 6 | Q2<br>Whole population |
| 16 | Nguyen V, Lewis K, Gilbert R, De Stavola B, Dearden L. The impact of early special educational needs provision on later hospital admissions, school absence and education attainment: A target trial emulation study of children with isolated cleft lip and/or palate. *PLoS One* 2025;20:e0327720. https://doi.org/10.1371/journal.pone.0327720 | 10 | Q3 |
| 17 | Nguyen VG, Lewis KM, Gilbert R et al. Early special educational needs provision and its impact on unplanned hospital utilisation and school absences in children with isolated cleft lip and/or palate: a demonstration target trial emulation study protocol using ECHILD [version 1; peer review: 1 approved, 2 approved with reservations]. *NIHR Open Res* 2023, 3:54 (https://doi.org/10.3310/nihropenres.13472.1) | 10 | Q3<br>protocol |
| 18 | Vincent Nguyen, Kate Lewis, Ruth Gilbert, Bianca De Stavola[1*], Lorraine Dearden. Early special educational needs provision and health and educational outcomes during primary school in children with cerebral palsy. *NIHR Open Res* 2025, **5**:65 (https://doi.org/10.3310/nihropenres.14015.1 | 9 | Q3 |
| 19 | Andrea Aparicio Castro, Bianca De Stavola, Lorraine Dearden. Assessing the short- and long-term effects of Special Education Needs (SEN) provision on unauthorised absences: a methodological comparison of causal contrasts and estimation methods. (in preparation). | 6 | Q3 |
| 20 | Lorraine Dearden, Andrea Aparicio Castro, Kate M. Lewis,Vincent G. Nguyen, Bianca De Stavola The causal impact of special educational needs on education and health outcomes in England: a practitioner's guide. (in preparation)<br><br>Bianca L De Stavola, Andrea Aparicio Castro, Vincent G. Nguyen, Kate Lewis, Lorraine Dearden, Ruth Gilbert, on behalf of the HOPE study team. Data Notes: Challenges in addressing causal questions using administrative data. . *Int J Popul Data Sci* – Data Notes (submitted Jan 2026) | 6 | Q3 |
| 21 | Gains, H., Winterburn, I., Saxton, J., Matthews, J., Farr, W., Black-Hawkins, K. (2025). Identification, assessment and provision of special education needs in England: a cross-sectional survey to compare perceptions of young people, parents/carers and professionals. European Journal of Special Needs Education, 1–17. https://doi.org/10.1080/08856257.2025.2491192 | | Q4<br>Quantitative online survey |
| 22 | Albajara Saenz, A., Winterburn, I., Matthews, J., Burn, A. M., Ford, T & Saxton, J. Lessons from Local Area SEND Inspections: A Content Analysis of Ofsted Outcome Letters. British Educational Research Journal (under review). | | 4<br>Mixed methods |
| 23 | Jacob Matthews, Isaac Winterburn, Jennifer Saxton, Nazneem Nazeer, Eleanor Chatburn, Ariadna Albajara Sáenz, Miyuki Komachi, William Farr, Kristine Black-Hawkins, Tamsin Ford. Exploring experiences of the English special educational needs system through an online survey of young people, and parents and carers. British Journal of Special Educational Needs https://nasenjournals.onlinelibrary.wiley.com/doi/full/10.1111/1467-8578.70043 | | 4<br>Quantitative online survey |
| 24 | William Farr, Isaac Winterburn, Jacob Matthews, Jennifer Saxton, Tamsin Ford. Surveying the Professional Experience of Special Educational Needs Provision in England. British Journal of Special Education, 2025(Dec); https://doi.org/10.1111/cch.70227. | | 4<br>Quantitative online survey |
| 25 | Saxton, J., Matthews, J., Winterburn, I., Casey, H., Barnes, S., Zylbersztejn, A., Hall, P., Tripp, C., Black-Hawkins, K. and Ford, T. Exploring the experiences and outcomes of children and young people receiving support for special educational needs over time in England: a qualitative study. In Frontiers in Education (Vol. 10, p. 1564583). Frontiers. doi: 10.3389/feduc.2025.1564583 | | 4<br>Interviews with children with SEND |
| 26 | Saxton, J., Winterburn, I., Matthews, J., Anderson, J., Farr, W., Minhas, S., Smith, S., Ford, T. Right support, right place, right time; right mess!' Professionals' views on factors influencing the SEND system and outcomes for children and families in England: A qualitative study. Archives of Public Health (under review). | | 4<br>Focus groups with SEND professionals |
| 27 | Saxton, J., Albajara Saenz, A., Williams, O., Matthews, J., Winterburn, I., Chatburn, E., Nazeer, N., Black-Hawkins, K., Ford, T. Examining local level variation in Special Educational Needs and Disabilities (SEND) service provision and associated data sources in England: A scoping review. Humanities, Social Science & Communication. 2025(Dec); https://doi.org/10.17863/CAM.123812 | | 4<br>Scoping review |
| 28 | Saxton, J., Barnes, S., Gains, H., Chatburn, E., Ford, T. Annual trends in LGSCO complaints and outcomes relating to Special Educational Needs and Disabilities in England: 2018 to 2023. Research Papers in Education (under review) | | 4 Quantitative analysis |

Continued

| No. | Paper Name | Analysis cohort | Question (phenotype-colour coded) |
|---|---|---|---|
| 29 | Saxton, J., Burn, A.M., Zhang, X., Toulmin, H., Parker, J., Casey, H., Matthews, I., Tripp, C., Barnes, S., Hall, P., Black-Hawkins, K., Gains, H., Ford, T. Barriers, enablers and outcomes reported by parents engaged with the special educational needs system in England: A qualitative study. PlosOne, 2025(Nov); e0335606. https://doi.org/10.1371/journal.pone.0335606 | | 4 Interviews with parent-carers |
| 30 | Matthews, J., Black-Hawkins, K., Basu, A., Necula, A-I., Downs, J., Ford, T. & Saxton, J.; (2024). To what extent do England's local offer websites adhere to the statutory guidance as set out in the special educational needs and disabilities code of practice? British Educational Research Journal, 50, 1724–1740. https://doi.org/10.1002/berj.3996 | | 4 Mixed methods analysis |
| **Blogs** | | | |
| 31 | Jacob Matthews, Kristine Black-Hawkins, Arina Basu, Andreea-Ioana Necula, Jonny Downs, Tamsin Ford, Jennifer Saxton. Research shows "critical information gaps" in most SEND local offer websites, including EHCP eligibility criteria. https://www.specialneedsjungle.com/research-critical-information-gaps-send-local-offer-websites-ehcp-eligibility-criteria/ | | Blog based on analysis of Local Offer for SEND websites |
| 32 | Ruth Gilbert, Kate Lewis, Will Farr. Special educational needs policy requires research infrastructure. BERJ Jan 2025. https://www.bera.ac.uk/blog/special-educational-needs-policy-requires-research-infrastructure | | Policy blog |
| 33 | Tamsin Ford & Jennifer Saxton, December 2022. Our three rights-based wishes for reforming SEND services in England. https://www.place2be.org.uk/about-us/news-and-blogs/2022/december/our-three-rights-based-wishes-for-reforming-send-services-in-england/ | | Blog for users of services |
| **Key finding flyers** | | | |
| 34 | Sarah Barnes, Jacob Matthews, Isaac Winterburn, Jennifer Saxon, Kristine Black-Hawkins, Tamsin Ford, December 2022. Key findings: Children and Young People's Survey https://www.ucl.ac.uk/population-health-sciences/sites/population_health_sciences/files/hope_study_-_cyp_survey_key_findings_flyer.pdf | | Layperson/visual summary |
| 35 | Sarah Barnes, Jacob Matthews, Isaac Winterburn, Jennifer Saxon, Kristine Black-Hawkins, Tamsin Ford , December 2022. Key findings: Parents and Carer's Survey https://www.ucl.ac.uk/population-health-sciences/sites/population_health_sciences/files/hope_study_-_parent_carer_survey_key_findings_flyer.pdf | | Layperson/visual summary |
| 36 | Sarah Barnes, Jacob Matthews, Isaac Winterburn, Jennifer Saxon, Kristine Black-Hawkins, Tamsin Ford, December 2022. Key findings: SEND Professional's Surve https://www.ucl.ac.uk/population-health-sciences/sites/population_health_sciences/files/hope_study_-_wider_stakeholder_group_survey_key_findings_flyer.pdf | | Layperson/visual summary |
| 37 | Sarah Barnes, Jacob Matthews, Isaac Winterburn, Jennifer Saxon, Kristine Black-Hawkins, Tamsin Ford, December 2022. Key findings Survey Summaries https://www.ucl.ac.uk/population-health-sciences/sites/population_health_sciences/files/hope_study_-_national_surveys_key_findings_poster.pdf | | Layperson/visual summary |
| 38 Code | Code used for analyses can be found referenced in papers or below:<br>1. In the ECHILD code list repository https://code.echild.ac.uk/<br>2. In the UCL Child Health Informatics Group repository for the HOPE study eg: https://github.com/UCL-CHIG/HOPE_neurodisability<br>3. By contacting authors | | Code used in analyses |
| 39 | Written evidence submitted by Department of Psychiatry, University of Cambridge to Parliamentary Inquiry: 'Solving the SEND Crisis' https://committees.parliament.uk/writtenevidence/137082/pdf/ | | Evidence submission to Parliament |
| 40 | Written evidence submitted by UCL Great Ormond Street Institute of Child Health to Parliamentary Inquiry: 'Solving the SEND Crisis' https://committees.parliament.uk/writtenevidence/136742/pdf/ | | Evidence submission to Parliament |

# Appendix 5: Methods and key findings for Question 4: What do service experiences and policies tell us about the process and delivery of SEND provision?

Summaries of sub-study findings mapped to: SEND identification, assessment of need, provision, outcomes, local service capability and national policy context.

| Sub-study | Method | SEND identification | Assessments of need | Received provision | Outcomes | Local service capability | Local services and national policy |
|---|---|---|---|---|---|---|---|
| **Qualitative studies**<br>Right support, right place, right time; right mess!' Professionals' views on factors influencing the SEND system and outcomes for children and families in England: A qualitative study (under review) [54].<br><br>Appendix 4 paper no.26 | Focus group discussions (N=6) with 35 SEND professionals, using a topic guide co-developed with parents of children with SEND. | • Initial identification of additional needs is improving in the classroom, especially with well trained, experienced SENCOs.<br>• Complexity of SEND is increasing.<br>• There are increasing numbers of children presenting to services with SEND.<br>• Quieter children with unmet needs may be overlooked in favour of disruptive children.<br>• Some professionals view the increase in SEND presentations as due to a general worsening of social circumstances, whilst others think we are better at recognising conditions. | • Interagency working is seriously impaired, which causes delays to assessments and diagnoses.<br>• Poor information sharing systems, low capacity to put together coordinated responses, poor working relationships, logistical problems of meeting, lack of specialists, and lack of shared understanding of what a child's needs are. Therefore, lots of referrals 'bounce back' which harms family's trust in professionals.<br>• There are insufficient numbers of trained professionals to implement the system properly. | • Support is often delayed.<br>• Lack of support in school or inappropriate educational placements are common and harmful for children.<br>• SEND provision depends on parent understanding of the system, advocacy ability and financial resources.<br>• Trust and good relationships with children and families are important for SEND provision, but are usually fraught, characterised by "mistrust", and worsen in the "limbo period" of waiting.<br>• The system should much earlier prepare young people with SEND for adult life, higher education and employment.<br>• Professionals are being taken away from preventive work to deal with EHCP assessment and plan related paperwork.<br>• There are ongoing disputes between professionals and LAs, and families and LAs about provision.<br>• Decisions based on funding rather than need. | • Long-term harm to parent and child mental health from delays and navigating the system.<br>• Families face out of pocket expenditure pursuing diagnoses and gathering evidence for tribunals.<br>• Children from families who cannot advocate are missing from the system, worsening outcomes and increasing inequalities in health and education.<br>• Unmet needs mean that some children never have a chance to feel successful and be proud of their achievements.<br>• Relationships between professionals and families, and between professionals are often very poor. | • Services are patchy and inconsistent because there is growing demand and more bureaucracy than ever before, with fewer SEND professionals and less money available to meet requirements.<br>• Information-sharing systems, standardisation of documents and processes, and interagency meetings improve quality/consistency of SEND activities. | • SEND provision operates within a broader system of national education which is not suitable for some children (e.g. curriculum demands, focus on exams, narrow subject focus, mainstream classroom environments).<br>• Other policies such as forced academisation, and stringent school attendance expectations can be indirectly and directly harmful for children with SEND.<br>• Many professionals are being expected to task shift (e.g. teachers and mental health provision) to compensate for England-wide gaps/delays in CAMHS services.<br>• There are too few educational psychologists for the SEND system to work and preventive services and early interventions to take place.<br>• SEND-related discrimination in the employment sector needs to be addressed. |

Continued

| Sub-study | Method | SEND identification | Assessments of need | Received provision | Outcomes | Local service capability | Local services and national policy |
|---|---|---|---|---|---|---|---|
| Barriers, enablers and outcomes reported by parents engaged with the special educational needs system in England: A qualitative study (under review) [55].<br><br>Appendix 4 paper no.29 | One-to-one interviews with N=22 parents. Drawn life 'timelines' were used to gain a comprehensive picture of participants' experiences of engaging with the system over time. | • Children with SEND are often 'unseen and unheard', misunderstood by school staff and mislabelled as naughty which could delay identification – particularly autism and ADHD, as well as children with communication difficulties. | • Several parents reported negative experiences of CAMHS assessments.<br>• Some parents reported unreasonably high thresholds to qualify for provision.<br>• Parents felt like they were ping pong balls in terms of referrals bouncing between departments. | • Legal protections and advocacy ability of parents and professionals are key enablers of SEND provision but come at a huge cost to families and legal processes can be very slow.<br>• Several parents reported premature discharge from CAMHS when children were still in crisis.<br>• Poor relationships and communication between professionals and with parents were common and undermined provision quality, caused delays, and made the system hostile.<br>• Decisions about provision were often based on poorly written and/or outdated plans.<br>• Parents excluded from multi-agency decisions which appeared to be against best interests of child. | • Positive outcomes for some: health, education and social, autonomy, independence.<br>• Negative outcomes for others: lost years of education and opportunities within settings, damage to parent and child mental health from delays and treatment by SEND professionals (particularly LAs), lack of aspiration for children by professionals also worsens their long-term prospects, parents losing out financially and in careers because of poor provision.<br>• Parents who cannot 'fight' may disengage – worsening inequalities. | • Inconsistent definitions of SEND at LA level (e.g. dyslexia).<br>• Variable processes at LA level in terms of when you can apply for ECH assessments.<br>• Variable thresholds for care/eligibility. | • Educational policies lack long-term vision for children with SEND.<br>• Lack of safety nets within health and social care for when CYP reach adulthood and parents can no longer provide intensive support. |

Continued

| Sub-study | Method | SEND identification | Assessments of need | Received provision | Outcomes | Local service capability | Local services and national policy |
|---|---|---|---|---|---|---|---|
| Exploring the experiences and outcomes of children and young people receiving support for special educational needs over time in England: a qualitative study [56].<br><br>Appendix 4 paper no.25 | One-to-one interviews (with 15 children and young people aged 13-25), with SEND. A timeline approach was used in conjunction with a semi-structured interview schedule. | • Late identification due to low awareness of some conditions (e.g. autism in girls, which may present differently to boys).<br>• Most children wanted to be identified and supported much earlier.<br>• Many children and young people said they were not listened to about their needs. | • Many children spent years on waiting lists for CAMHS and for diagnoses, often unsupported in the interim. | • Primary schools were described by some as being able to provide good needs-led support.<br>• Some SENCOs stood out as being able to offer effective tailored provision, whilst others were criticised.<br>• Some schools would not offer support without a diagnosis.<br>• Parent and child advocacy ability were critical for getting provision in place.<br>• Some provision was inappropriate and ineffective. | • Sensory overload was commonly reported, and provision that enabled children to manage this was effective for improving educational and mental health outcomes.<br>• Time spent waiting for assessments and interventions was harmful for education and mental health.<br>• Many children reported positive effects of provision on their independence.<br>• Exam-support and mentoring was helpful.<br>• Transitions that were not well managed (e.g. primary to secondary) could exacerbate problems.<br>• Effectiveness of provision was strongly influenced by school context, ethos and senior leadership.<br>• Individually tailored provision was more helpful than generic. | • Lack of local specialist SEND and CAMHS professionals were causing delays to provision and worsening the outcomes of children.<br>• School resources sometimes dictated the quality of provision (e.g. physical space for sensory room). | • Many children said teachers would benefit from additional neurodiversity training.<br>• Many children said exams were an unfair format for them to demonstrate their skills. |
| **Sub-study** | **Method** | **Initial identification (4a)** | **Assessments and planning (4b)** | **Provision (4c)** | **Outcomes (4d)** | **Local service capability (4e)** | **National policy context (4f)** |

Continued

| Sub-study | Method | SEND identification | Assessments of need | Received provision | Outcomes | Local service capability | Local services and national policy |
|---|---|---|---|---|---|---|---|
| **Online surveys of children and young people, parents/carers and SEND professionals** | | | | | | | |
| Identification, Assessment and Provision of Special Education Needs in England: A cross-sectional survey to compare perceptions of young people, parents/carers and professionals [57].<br><br>Appendix 4 paper no.21 | Self-report, cross-sectional surveys completed by young people with SEND (N=77), parents (N=770) and SEND professionals (N = 863). | • Parents rated their perception of identification services as positive (28%), neutral (19%) and negative (53%).<br><br>• SEND professionals rated their perception of providing services for identification as positive (34%), neutral (27%) and negative (28%).<br><br>• Most parents disagreed that professionals had enough training in SEND identification.<br><br>• Most SEND professionals reported they did have appropriate training to identify children and young people who may have SEND. | • Few parents agreed that enough information was provided to them about their child's additional needs during assessment from teaching staff (26%), health services (32%), or the LA (16%).<br><br>• Few parents agreed that enough information was provided directly to their child from education staff (24%), health services (26%), or the LA (12%).<br><br>• 45% of professionals disagreed that the assessment process adequately supported families who were less able to advocate for themselves. | • Experiences of provision were split between negative and positive.<br><br>• 49% of parents rated their overall perception of provision as negative or neutral (19%), whilst 25% reported it to be positive.<br><br>• Most children agreed that they "would have liked extra support for my learning earlier in my education" (74%) and fewer endorsed neutral (9%) or disagreed with the statement (10%).<br><br>• Perceptions of SEND provision were mixed for SEND professionals; 45% rated provision as positive, neutral (28%) and negative (22%). | • This paper does not report on outcomes. | • Most children (71%) have not heard about the LO for SEND.<br><br>• The LO website was the least common source of information for parents (1%). Instead, parents used online forums (21%), social media (19%), independent advocates (18%) and other parents (16%) for ongoing information gathering around their child's SEND.<br><br>• Most parents (72%) disagreed that there are enough support services available to parents of children with SEND.<br><br>• Most SEND professionals had heard of the LO (83%). However, only 39% agreed their LO provides all the information it is supposed to, and 23% agreed their LA was able to provide all the SEND services it was supposed to. | • Whilst professionals rate their training in SEND identification as adequate, parents have negative views of professionals' level of knowledge and skills. This suggests that training might not always be effectively translated into practice.<br><br>• Parents say there is inadequate support for families who are less able to advocate for themselves and SEND provision depends on financial/social capital.<br><br>• Professionals say that young people are not adequately involved in their assessments at present, despite this being a statutory expectation. |

Continued

| Sub-study | Method | SEND identification | Assessments of need | Received provision | Outcomes | Local service capability | Local services and national policy |
|---|---|---|---|---|---|---|---|
| Exploring the experiences of the English Special Educational Needs System through an online survey of young people, and parents and carers [58].<br><br>Appendix 4 paper no.23 | Self-report, cross-sectional survey of young people with SEND (N=77) and parents/carers (N=770) | • Only a third of parents agreed that education, health and local authorities are supportive in identifying SEN.<br><br>• The three main barriers that parents reported to identification are long waiting lists, lack of understanding in education settings and lack of specialist SEND professional in their LA.<br><br>• Most (91%) children reported that their parents talk to them about their need for extra support, whereas only 51% agreed the same of teachers and health professionals (45%).<br><br>• In total, 47% of children were identified as needing extra support in pre-school (25%) or Key Stage One (22%). | • 80% of children trusted their parents to make the right decisions about their extra support needs, while only 42% trusted their teachers and 48% trusted health professionals.<br><br>• This indicates potential vulnerability for children without strong parental support.<br><br>• 48% of children felt involved in decision making during their assessment process.<br><br>• Children described their experience of assessment as positive (40%), frustrating (32%), and stressful (25%). Words describing negative experiences were more commonly selected. | • Satisfaction for support provided is low among parents: 41% agree that their child's EHCP responds to all their needs and 34% agree that their child's EHCP or SEN statement matches what their child receives.<br><br>• 87% of children reported that their parents listened to what they said about their learning needs, whilst 55% agreed the same of teachers.<br><br>• 62% of children reported that their teacher included them in lessons.<br><br>• 54% of children believed their extra support helped them access the same classes as their peers, demonstrating the importance of timely and accurate provision. | • Survey responses suggest that children EHCPs lack information about future goals and aspirations and are often not appropriately ambitious.<br><br>• 35% of parents agreed that their child's EHCP or SEN statement includes appropriately ambitious learning outcomes.<br><br>• 49% of parents agreed that future goals and aspirations are included in their child's EHCP or SEN statement. | • A minority of parents reported that key service providers had a good or very good understanding of what support their youngest child with SEND required: education settings (26%), health services (20%), and local authorities (14%).<br><br>• Most parents reported negative experiences when liaising with LAs about SEND provision.<br><br>• 38% of parents had paid for private assessment, suggesting lack of availability or satisfaction with the public sector assessments. | • No relevant data. |

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| Sub-study | Method | SEND identification | Assessments of need | Received provision | Outcomes | Local service capability | Local services and national policy |
|---|---|---|---|---|---|---|---|
| Surveying the Professional Experience of Special Educational Needs Provision in England (under review) [59].<br><br>Appendix 4 paper no. 24 | Self-report, cross sectional survey of SEND professionals (N=770). | • A minority (38%) of SEND professionals agreed that there is effective communication between agencies involved in SEND identification.<br><br>• There is variation between professionals from different sectors (e.g. in their self-reported knowledge and confidence).<br><br>• 46% of LA staff agreed that there is effective communication during identification, followed by 44% of health professionals and 36% of education staff.<br><br>• Most professionals felt confident in identifying children with SEND (86%). Confidence was highest amongst health professionals (91%) followed by LA professionals (88%), education professionals (85%) and other professionals (79%). | • This study does not report on formal assessments and plans. | • Most professionals (63%) felt neutral or disagreed that they can provide sufficient support to families in their LA most of the time.<br><br>• Half of all professionals (50%) felt confident most of the time in designing and providing services for children. This was consistent across LA, health, education and other professionals.<br><br>• 71% of professionals felt confident in communicating with families about SEND provision, with higher agreement from LA professionals (85%) and lowest agreement from healthcare (63%). | • This study does not report on outcomes. | • Only 20% of professionals felt they had sufficient time and resources to deliver good quality SEND for all children with SEND in their LA.<br><br>• Over 95% over professionals reported at least one barrier to providing good quality SEND.<br><br>• The most frequently selected barriers were lack of LA funding (20%), length of waiting lists (18%), insufficient access to SEND specialists (14%) and excessive caseload (10%).<br><br>• The least selected barriers were burnout (1%), communication with parents (1%), poor senior leadership (1%), relationships with Social Care professionals (1%), difficulties interpreting and applying the SEND CODE of practice (1%), relationships with PCs (0.8%) and relationships with education professionals (0.5%). | • There were overall mixed reports about whether professionals had sufficient training to design and deliver good quality SEND provision in the LA where they work(ed) most of the time.<br><br>• Over half (58%) agreed that they do have sufficient training.<br><br>• Views on having sufficient training were similar across education (60%), LA professionals (60%) and health (54%). However, only 44% of other professionals agreed. |
| **Sub-study** | **Method** | **Initial identification (4a)** | **Assessment and planning (4b)** | **Provision (4c)** | **Outcomes (4d)** | **Local service capability (4e)** | **National policy context (4f)** |

Continued

| Sub-study | Method | SEND identification | Assessments of need | Received provision | Outcomes | Local service capability | Local services and national policy |
|---|---|---|---|---|---|---|---|
| **Document review**<br>Examining local level variation in Special Educational Needs and Disabilities (SEND) service provision and associated data sources in England: A scoping review (under review) [60].<br><br>Appendix 4 paper no.27 | A scoping review that identified N=18 peer reviewed studies, N=105 grey literature studies and compiled open access data sources including SEND data at LA or Multi-academy Trust level. | • Inconsistent and inequitable identification of SEND within a single MAT.<br><br>• Inconsistent identification of autism at LA level, from different phenotypic prevalence and/or 'differences in detection or referral'.<br><br>• Role of the SENCO is crucial to identification and onward referrals, but scale and capacity to carry out work is hugely variable - wide array of tasks, expectations of multiple stakeholders & differing seniority. | • Quality of EHCP processes and documents were undermined in multiple ways.<br><br>• EHCPs not always needs-based, influenced by need type (e.g. SEMH harder to validate), parental advocacy, SENCO experience, interagency working, inconsistent application of the law.<br><br>• Outsourcing of EHCP writing affects quality and co-production with families. 'Copy-paste' plans & written outcomes often not functional or SMART, lack of tailoring.<br><br>• Inconsistent methods being used and barriers to meaningfully capturing child voice/preference in EHCPs.<br><br>• Inspections found that excessive bureaucracy was increasing waiting times. | • 'Gap between ideology and implementation' of CFA, in context of no additional staff or funding.<br><br>• TAs are most confident, effective, and can apply specialist training when they are linked with LA specialist teams.<br><br>• Preparation for adulthood programmes should start earlier (by 13-14 years) and the offer should be broadened beyond education settings to promote belonging and create mentoring and employment opportunities.<br><br>• Clear interagency communication is required to ensure successful transition from child to adult health services.<br><br>• Post-16 options provided by LAs are too limited. Parents wanted an impartial list of options, and not to be steered by LAs to inappropriate or funding-based placements, and LAs to listen to children's preferences.<br><br>• Large variation at LA level about awareness of the LO of SEND provision and uptake of related services such as short breaks/respite care. | • Negative outcomes for parents: complaints & redressal data shows high parent distress from engaging with statutory processes (delays, protracted process, unmet needs and expectations, fear for the future for children).<br><br>• Financial outcomes for LAs: Mediation (not about placement) may save LAs money overall for less complex cases as can avoid more costly tribunals (low quality evidence).<br><br>• Positive outcomes from post-16 schemes when LAs are involved in apprenticeships and internships as it allows effective targeting of underserved groups.<br><br>• Educational outcomes: Children with SEND are disproportionately excluded, and there is no way appeal or influence the new placement that is named; in parallel LAs have low understanding about alternative provision locally, affecting the quality of commissioning and placement decisions. | • Staff burnout, inconsistent processes, poor interagency working, and low quality LOs.<br><br>• Funding cuts and limited training and resources locally drive increasing local variation in provision.<br><br>• High local variation in the % of EHCPs, mediation and appeals against LA decisions relative to child population.<br><br>• Increasing demand for SEND services, which many LAs were not ready for.<br><br>• Feedback by service users about the LO for SEND (all from low quality research) suggests between-LA variation in people's satisfaction with it the corresponding website (the extent it was useable, with accurate and up to date information).<br><br>• There is a wealth of unused administrative data that would enable meaningful reporting on local variation in SEND identification and provision, including disaggregating by socio-demographic factors to examine equity of service coverage and use. | • Professionals need 'clear guidelines and systematic, standardised training' to improve plans & implementation.<br><br>• Switch from Independent Appeal to Independent Review Panels, and government drive to convert schools to academies negatively affected children who were excluded from school (e.g. LAs less able to challenge schools about decisions).<br><br>• Academies often affected by reporting delays about newly identified children with SEND compared to previous system.<br><br>• SEND CoP guidance led to fewer children being recorded in SEN registers, in turn resulting in fewer specialist teachers in some LAs. |

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| Sub-study | Method | SEND identification | Assessments of need | Received provision | Outcomes | Local service capability | Local services and national policy |
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| **Document review**<br>To what extent do England's local offer (LO) websites adhere to the statutory guidance as set out in the special educational needs and disabilities code of practice [61].<br><br>Appendix 4 paper no.30 | Secondary content analysis of LO websites. Where possible analysis was also conducted on annual reports, policy documents, surveys and meeting minutes provided on LO websites. | • LO websites are a potentially crucial first information source for people in the early stages of noticing their child's additional needs - but there are information gaps on LO websites, which contravene current SEND legislation.<br><br>• LO websites commonly lack accessibility features, failing to meet the needs of many service users. This may exacerbate sociodemographic inequalities by forming a barrier to information access. | • Across England, 89% of LO websites provide information about the EHCP process. However, only 47% of LAs provide eligibility criteria in clear, simple, plain language with bullet points or checklists. The language used on LO websites needs to be simplified to facilitate engagement of children and parents. | • There is high variation between LAs in the quality of LO websites. This reinforces the concern that SEND provision depends on a postcode lottery.<br><br>• Information on available health services is provided widely on LO websites, with all LAs providing information on services related to mental health.<br><br>• All LAs provided information on available schools, however only 73% included a transport policy statement.<br><br>• Only 31% of LO websites signpost to offline resources or alternative means for those with limited internet access. | • This paper does not report on outcomes. | • There is wide variation in the quality of LO websites, with some very poor examples and other websites that offer excellent content and navigability.<br><br>• There is evidence that many LAs included children and parents in developing the LO website. However, only 8% complied with the Equality Act when preparing the LO.<br><br>• Whilst 99% of LAs provide information about the option of having a personal budget, only 64% describe the services for which these budgets can be used. | • There is limited evidence for effective regional partnerships or information sharing, demonstrated by high variability of LO websites both within and between regions.<br><br>• The CoP states 'must' criteria as legal requirements. However, there is greater adherence to 'should' criteria, which are not legal requirements. Many LO websites require substantial updates to reach legal standards. |

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| Sub-study | Method | SEND identification | Assessments of need | Received provision | Outcomes | Local service capability | Local services and national policy |
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| **Document review** | | | | | | | |
| Lessons from Local Area SEND Inspections: A Content Analysis of Ofsted Outcome Letters (under review) [62].<br><br>Appendix 4 paper no.22 | Secondary content analysis of Ofsted/ CQC inspection letters (N=36 initial inspection letters and N=34 revisit letters). | • Most common strengths inspectors reported about SEND identification: Inter-agency working, health services/support and interventions, accurate, timely and early identification of needs.<br><br>• Common weaknesses also included health services, and accuracy of needs identification, as well as educational provision and support at school. | • Widespread problems with EHCP process often meaning the LA failed their inspection, and sometimes their reinspection.<br><br>• EHCP issues reported concerned: quality, timeliness, outcomes, accuracy, poor multi-agency input, lack of monitoring, leading to inappropriate provision. | • Most common strengths inspectors reported about meeting needs were inter-agency working, health services/support and interventions, and relationships with parents and carers.<br><br>• Common weaknesses were also relationships with parents, health services, as well as educational provision and support at school and EHCPs. | • Most common outcomes improved were educational/academic, employment and training, and educational provision and support at schools.<br><br>• Most common outcomes needing improvement: Leaders' awareness and system utilisation and educational/ academic outcomes and progress. | • Overlap in common strengths and weaknesses indicates variation between LAs.<br><br>• Most common area of significant weakness triggering a written statement of action by LAs were: LA leaders and leadership (91.2% of letters), SEND provision and support, and EHCPs (both in 82.4% of letters).<br><br>• In revisits following a written statement of action (87.1%) were found to make sufficient progress improving leadership, (82.4%) improved SEND support and (82.4%) improved EHCPs. | • Our data provide benchmarks for current practices at LA level and identify common areas of strength and concern that can be monitored in new iterations of the inspection framework being rolled out across England. |

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| Sub-study | Method | SEND identification | Assessments of need | Received provision | Outcomes | Local service capability | Local services and national policy |
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| **Document review** | | | | | | | |
| Annual trends in Local Government and Social Care Ombudsman complaints and outcomes relating to Special Educational Needs and Disabilities in England: 2018 to 2023 (under review) [63].<br><br>Appendix 4 paper no.28 | Secondary analysis of LGSCO administrative data, 2018 to 2023. Descriptive statistics were generated to explore variation in SEND-related complaints to the ombudsman in England by year, complaint type, and subsequent outcomes (upheld, not upheld, not considered). | • This paper does not report on initial identification. | • Complaints regarding the assessment and reviews of needs fall within the "SEN" complaints category and this was the most frequent type of complaint across all data years.<br><br>• The rate of SEN related complaints (complaints per 10,000 pupils with EHCPs or with 'SEN support') are increasing and accounting for an increasingly large proportion of complaints relative to other causes. | • Absolute numbers of complaints in all categories (alternative provision, transport, COVID, school admissions, school exclusions, SEN, and other) have risen steadily since 2021.<br><br>• The complaint rate (complaints per 10,000 pupils with EHCPs or with 'SEN support') increased more than four-fold, from 1.42 to 6.12. | • At least 80% of SEN and alternative provision complaints have been upheld in the favour of parents over time.<br><br>• School transport complaints were increasingly upheld over time (stabilising at around 75%).<br><br>• There were no complaints within the LGSCO remit about school exclusions. | • There is considerable variation in complaint rate across LAs.<br><br>• Over time there is an increasing complaint rate in an increasing number of LAs.<br><br>• Over time, there are fewer LAs receiving 0 complaints a year.<br><br>• LGSCO SEN complaints category reflects complaints on the provision of EHCP plans, transitions, budgets and direct payments. It is therefore not possible to isolate whether the assessment of children's SENs is driving the increase in complaints in this category. | • LGSCO complaints categories include alternative provision, COVID-19, school admissions, school exclusions, school transport, SEN and other complaints.<br><br>• COVID-19 complaints upheld have increased over the data years from 71% in 2020/21 to 88% in 2022/23.<br><br>• Other complaint types show slight decreases in 2020/2021, which may be because the LGSCO did not consider complaints for a 3-month period (February to April 2021) due to COVID-19 restrictions. |

Note: 'children' is used to refer to children and young people aged 13 to 25 years and 'parents' is used to refer to parents and carers.

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