Paediatric and Perinatal Epidemiology

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Educational Attainment of Children With Major Congenital Anomalies During Primary School in England: A Population Cohort Study

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ABSTRACT

Background: Major congenital anomalies (CA) affect 2.3% of livebirths and are associated with lower educational attainment. Understanding attainment trajectories throughout primary school would inform parents, schools and organisations and help plan support.

Objectives: We compared school enrolment and attainment at ages 5, 7 and 11 in children with different CA and their peers in England using the Education and Child Health Insights using Linked Data database.

Methods: We included all singleton children born in NHS-funded hospitals from September 2003 to August 2008 who enrolled in state-funded schools at ages 4–5. CA were identified from hospital diagnoses, procedures or death records. We described school enrolment, school-readiness, the percentage who sat curriculum assessments and who achieved expected English and Maths attainment at three ages. We estimated risk ratios of children with CA achieving expected attainment compared with peers, adjusting for sociodemographic factors.

Results: Of 2,351,589 children enrolled at age 5, 78,847 (3.5%) had CA. At age 11, 88.7% of enrolled children with CA sat assessments versus 97.2% of peers. Proportionally fewer children with CA (45.7%) were school-ready at age 5 versus peers (57.0%). For English, 56.9%, 55.4% and 65.3% of children with CA achieved expected levels at ages 5, 7 and 11 respectively, consistently 11%–12% fewer than peers; similar gaps persisted for Maths. Children with CA were less likely than peers to achieve expected attainment (adjusted risk ratio [aRR], 0.86, 95% confidence interval [CI] 0.85, 0.86), but this varied substantially (aRR 0.01, 95% CI 0.01, 0.02 for Down syndrome; aRR 1.04, 95% CI 0.96, 1.12 for unilateral renal agenesis).

Conclusions: Attainment gaps between children with CA and peers remained unchanged across subjects and ages, with proportionally fewer sitting assessments at age 11. Better monitoring and support for these children from school entry could help optimise learning experiences and fulfil their academic potential.

1 | Background

Major congenital anomalies (hereafter CA) are inborn structural, chromosomal or genetic disorders with significant medical, functional or social consequences for individuals. Many CA are rare diseases, affecting under 1 in 2000 people, but collectively they occur in 2.3% of births in England [1]. Although more children with CA are surviving to school age [2], fewer achieve expected levels of attainment compared with their peers [3–5]. Complex health needs, higher school absence rates, inherent learning disabilities, and inadequate special educational needs (SEN) support potentially contribute to adverse outcomes, including those with non-chromosomal CA such as cardiac defects, orofacial clefts or spina bifida [6–8]. A recent study using linked education and regional CA registries' data in England showed that subject attainment rates at ages 11 and 16 for children with structural CA were on average 5%–7% lower than their peers [9].

We aimed to describe the attainment trajectories for children with and without CA in England by following whole-population cohorts through key stages of primary school (ages 4–11 years). Understanding changes in the rates of school enrolment, curriculum assessments and attainment for children with different CA will provide evidence to inform timely support, enrich their educational experience and maximise their academic potential during these formative years. This project contributes to the Health Outcomes of young People in Education (HOPE) research programme, described elsewhere [10].

2 | Methods

2.1 | Study Design

This is a population-based retrospective cohort study using linked administrative data from the ECHILD (Education and Child Health Insights from Linked Data) database [11].

2.1.1 | Data Sources

ECHILD contains routinely-collected data on hospital admissions from Hospital Episode Statistics (HES) linked to education data from the National Pupil Database (NPD). HES captures 97% of births in NHS-funded hospitals in England and 98%–99% of secondary care contacts (approximately 14.7 million individuals born 1995–2020 in the version used) [10, 11]. HES includes demographic information, hospital stays, coded diagnoses and procedures, and linked causes of death from civil registrations [12]. The NPD holds information on children attending state-funded schools in England between the ages of 4–18 years from academic year 2001/02 [13]. Data include teacher-assessed outcomes and national test marks at different key stages, pupils' ethnicity, deprivation indices, free school meals eligibility (FSME) and geographical information.

2.1.2 | Cohort Selection

We included all singleton children born in NHS-funded hospitals between 1st September 2003 and 31st August 2008 who were enrolled in Reception year (age 4/5) in state-funded schools, based on the January school census. We excluded children who were two or more years outside of the expected age for their school year. Children were followed up until the end of primary school (age 11), enrolment ceased or death (whichever was earlier).

2.2 | Major Congenital Anomalies

CA subgroups were defined by International Classification of Diseases 10th Revision (ICD-10) diagnosis codes according to the EUROCAT (European network of population-based registries for the surveillance of congenital anomalies) guide version 1.4 [14]. We used alternative codelists combining diagnosis and procedure codes for severe congenital heart defects (CHD) [15], orofacial clefts [3, 6, 16], anorectal malformations [17] and hypospadias [18]; all except severe CHD produced more conservative birth prevalence estimates than EUROCAT. We searched for relevant diagnosis codes recorded before the first birthday and procedure codes (where specified), or causes of death up to the 12th birthday.

We described results for exemplar cardiac, orofacial, digestive, renal, and limb CA, CA associated with learning disabilities (e.g., congenital hydrocephalus, Down syndrome), and CA featured in previous studies using NPD data [3, 4]. The 'any CA' group encompassed additional cases not belonging to the featured subgroups, whilst some CA are nested within higher-order subgroups (e.g., Tetralogy of Fallot and CHD). For non-syndromic CA, we focused on the subset of children with isolated anomalies: structural defects occurring in the same organ system (e.g., polydactyly of hands and feet) classified according to a EUROCAT algorithm [19]. Children with CA in multiple organ systems not linked by a known sequence or chromosomal/genetic malformation were classified as having multiple CA; however these require clinical verification and form a heterogeneous group, and served only as comparators in sensitivity analysis (see below). CA subgroups are described in Table S1.

2.3 | Outcomes

In England, National Curriculum academic assessments are conducted at ages 5, 7 and 11 during primary school– interchangeably denoted as Early Years Foundation Stage Profile (EYFSP), Key Stage 1 (KS1) and Key Stage 2 (KS2) respectively. At EYFSP, children are assessed for reaching the Good Level of Development (GLD), a school-readiness indicator [20]. English and Maths attainment (whether children achieve the age-specific expected level) is based on teacher-assessments (EYFSP and KS1) and nationally marked tests (KS2). Further, subject z-scores (transformed from attained levels or test marks and standardised for each academic year cohort) were used to compare attainment across key stages. A unit z-score represented approximately 4–6 scale points (EYFSP), 4 points (KS1) and 9 marks (KS2) respectively. Assessment metrics are detailed in Table S2.

2.4 | Covariates

Birth and sociodemographic characteristics, including potential confounders of the association between CA and outcomes,

included: (from HES) sex at birth, academic year of birth, month of birth, maternal age at birth, birthweight, gestational age; (from NPD) ethnicity, income deprivation affecting children index (IDACI) quintile, FSME and region of residence. IDACI is a postcode-based measure of the proportion of children aged < 16 years living in income deprived families in each small area of England; ranked proportions were divided into five equal IDACI quintiles [21].

2.5 | Statistical Analysis

We quantified the number of children enrolled at ages 5, 7, and 11, and deaths during primary school (% relative to those enrolled at age 5). Using all enrolled children as the denominator, we reported: the percentage who (1) reached GLD, (2) were assessed, (3) achieved expected levels, and (4) the distribution of z-scores, for each subject and key stage, by CA subgroup.

Generalised linear models (Poisson distribution, log link and robust standard errors) were used to estimate risk ratios of achieving expected levels for English and Maths at EYFSP, KS1 and KS2, comparing children in CA subgroups to children without CA. We coded "not assessed" and "assessed but not achieved" as "not achieved". We controlled for sex, and then for sex and maternal age, ethnicity, IDACI quintile and FSME to provide adjusted risk ratios. Additionally adjusting for year and month of birth did not materially alter estimates as they were not associated with attainment and CA respectively. We did not adjust for birthweight and gestational age because they are likely downstream from CA [22, 23].

For selected CA subgroups and all CA combined, we fitted linear mixed models with random intercepts and random slopes to estimate the trajectories of z-scores, comparing children with and without CA, adjusting for the factors described above. Including interaction terms allowed the differentials by CA status and sex to vary with age. To reduce computation time, the reference group consisted of a random sample of 25% of children without CA. All analyses were performed using Stata version 18 (StataCorp LLC, Texas, USA).

2.5.1 | Missing Data

Missing sex was substituted with NPD-recorded gender. If region, FSME and IDACI were missing at age 5, we used the earliest non-missing record in any subsequent school census. Ethnicity was based on the modal value across all censuses. Children in census without assessment results were considered as not achieving the expected level. For all regression models, we analysed complete cases as < 5% of the total had any missing covariate value.

2.5.2 | Sensitivity Analysis

We compared outcomes for CA subgroups defined by EUROCAT and alternative codelists. We stratified attainment results by malformation type (isolated, multiple or chromosomal/genetic) to check that our results were consistent with expectations of isolated CA having better attainment. We estimated risk ratios using two populations: (1) all children

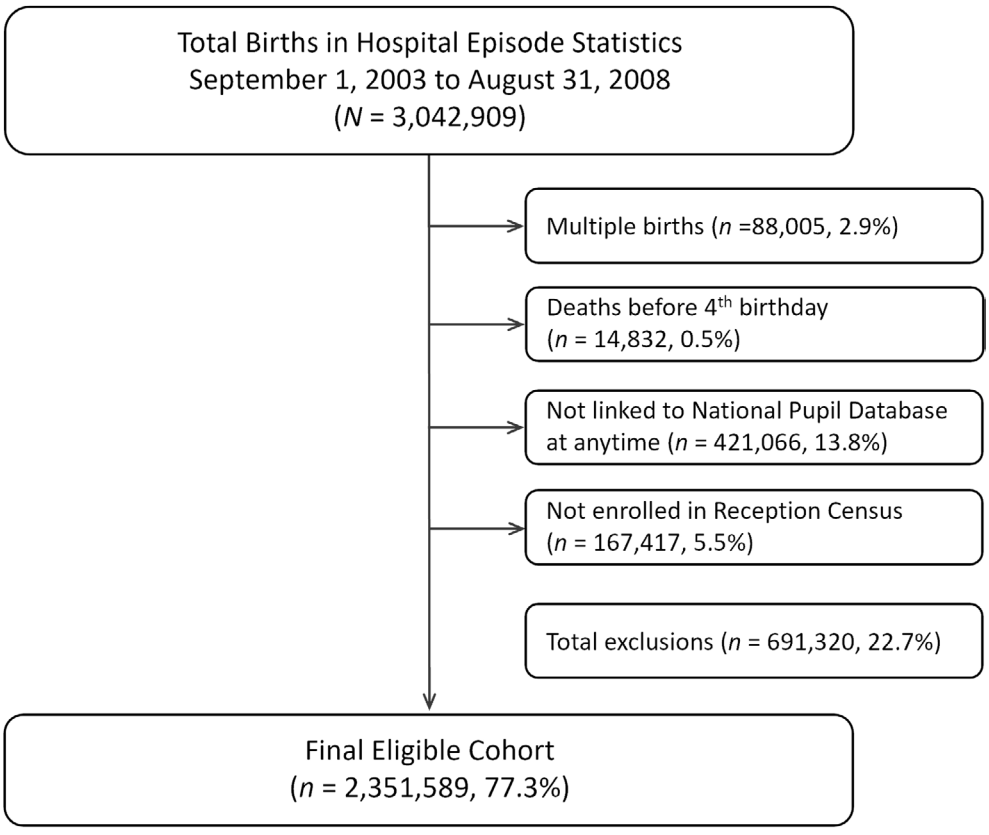


FIGURE 1 | Flowchart showing starting population, exclusions and final numbers included in study.

TABLE 1 | Birth prevalence and number included in study, by congenital anomaly subgroup and malformation type (denominator for birth prevalence, $N = 3{,}042{,}909$).

Subgroup	Number of cases in HES (prevalence per 10,000 births)	Enrolled in reception	Malformation type[a]		
			Isolated, %	Potential multiple, %	Genetic, chromosomal or other, %
Any congenital anomaly	105,514 (346.8)	78,847	71.5	8.2	20.3
Neural Tube Defects	833 (2.7)	510	53.9	42.5	3.5
Hydrocephalus	1180 (3.9)	701	55.6	39.2	5.1
Congenital Cataract	614 (2.0)	470	81.3	11.5	7.2
Congenital Heart Defects (CHD)[b]	23,792 (78.2)	15,852	71.7	16.1	12.2
Ventricular Septal Defect without severe CHD	5075 (16.7)	3673	71.6	14.6	13.8
Pulmonary Valve Stenosis without severe CHD	702 (2.3)	546	78.6	11.9	9.5
PDA as only CHD in term infants	4442 (14.6)	2611	79.2	15.3	5.5
Severe CHD[b]	6630 (21.8)	4283	69.8	14.0	16.2
Atrioventricular Septal Defect	1398 (4.6)	832	40.5	11.5	48.0
Tetralogy of Fallot	1162 (3.8)	826	63.9	17.9	18.2
Hypoplastic Left Heart	707 (2.3)	271	78.6	15.1	6.3
Respiratory	2187 (7.2)	1405	52.2	39.6	8.2
Orofacial clefts					
Cleft Lip	1117 (3.7)	982	87.0	10.7	2.3
Cleft Palate	1906 (6.3)	1653	62.6	11.9	25.6
Cleft Lip and Palate	1592 (5.2)	1378	78.8	14.9	6.2
Digestive System[b]	7692 (25.3)	5433	55.3	35.9	8.7
Anorectal Malformations	1021 (3.4)	780	25.5	58.8	15.6
Hirschsprung's Disease	730 (2.4)	602	75.4	15.3	9.3
Gastroschisis	1240 (4.1)	961	83.1	c	< 1.0
Unilateral Renal Agenesis	583 (1.9)	453	71.3	22.5	6.2
Congenital Hydronephrosis	5129 (16.9)	3973	88.9	8.4	2.7
Hypospadias	5118 (16.8)	4329	76.3	9.6	14.2
Club Foot—Talipes Equinovarus	3328 (10.9)	2565	86.3	10.4	3.3
Polydactyly	5129 (16.9)	4027	86.4	6.4	7.2
Syndactyly	2432 (8.0)	1918	80.6	13.6	5.8
Craniosynostosis	934 (3.1)	766	68.7	16.4	14.9

(Continues)

TABLE 1 | (Continued)

Subgroup	Number of cases in HES (prevalence per 10,000 births)	Enrolled in reception	Malformation type[a]		
			Isolated, %	Potential multiple, %	Genetic, chromosomal or other, %
Chromosomal Anomalies					
Down Syndrome	3023 (9.9)	2134	d	d	100.0
Turner Syndrome	190 (0.6)	135	d	d	100.0
Klinefelter Syndrome	89 (0.3)	73	d	d	100.0
Di George Syndrome	198 (0.7)	136	d	d	100.0
Karyotype XXX	55 (0.2)	40	d	d	100.0

Abbreviations: c, not presented due to suppressed quantity in adjoining cell; CHD, congenital heart defect; d, not applicable; HES, Hospital Episode Statistics; PDA, patent ductus arteriosus.
[a]As percentage of children included in study.
[b]Major group containing other individuals not in the selected CA shown below (indented).

enrolled at a given key stage; (2) a subset assessed at all three key stages; smaller differences were expected between the latter group and peers.

2.6 | Ethics

Permissions to use linked, de-identified data from Hospital Episode Statistics and the National Pupil Database were granted by the Department of Education (DR200604.02B) and NHS Digital (DARS-NIC-381972). Ethical approval for the ECHILD project was granted by the National Research Ethics Service (17/LO/1494), NHS Health Research Authority Research Ethics Committee (20/EE/0180 and 21/SW/0159), and UCL Great Ormond Street Institute of Child Health's Joint Research and Development Office (20PE06).

3 | Results

A total of 3,042,909 livebirths were extracted from ECHILD. Of 2,940,072 (96.6%) singleton children who were alive at their 4th birthday, 421,066 (13.8%) could not be linked to the NPD, whilst 167,417 (5.5%) linked to the NPD were not enrolled at age 5, leaving 2.35 million children in our study (Figure 1).

There were 78,847 (3.5%) children with CA. Amongst them, 71.5% had isolated CA, 20.3% had chromosomal, genetic, or non-system specific CA, whilst 8.2% had multiple CA (Table 1). Enrolment rates decreased similarly over time for children with and without CA, with 98.6% and 96.0% remaining enrolled by ages 7 and 11, respectively. Mortality during primary school was 0.4% in children with CA, 10-fold higher than peers (Table S3).

Males comprised 51.4% of children overall but 59.7% of those with CA (Table 2). Compared to children without CA, proportionally more children with CA were born < 37 weeks and had birthweight < 2500 g. Children with CA were more likely to have mothers < 20 or ≥ 40 years, be of Asian/Chinese or Black ethnicity, have FSME, and be in the lowest two deprivation quintiles. Most variables had no or relatively little missing data (< 4.0%), except for birthweight (23.0%) and gestational age (33.6%), with a slightly higher percentage for children with CA.

3.1 | Good Level of Development

Overall, 57.0% of enrolled children without CA reached GLD, compared with 45.7% of children with CA (Figure 2). Amongst isolated CA, congenital hydronephrosis, club foot, and polydactyly had the highest proportions reaching GLD (≥ 51.9%), 5% below their unaffected peers, whilst hypoplastic left heart (30.5%) and congenital hydrocephalus (22.1%) had the lowest. Apart from Karyotype XXX, syndromic CA showed the lowest GLD achievement rates (< 1% for Down syndrome). Males performed worse than females across CA, with 15% fewer reaching GLD on average (Table S4).

3.2 | Subject Attainment for English and Maths

English and Maths assessment rates for children with and without CA were broadly comparable up to KS1 (~99%), but declined considerably for children with CA at KS2 (Table 3). Attainment rates for children with CA in English rose from 56.9% (EYFSP) to 65.3% (KS2), but remained consistently 11%–12% lower than for their peers. Maths attainment rates remained stable but a similar gap existed (67% for children with CA, 78% for peers). Children with isolated renal anomalies, limb defects and cleft lip had the highest attainment rates, whereas those with congenital hydrocephalus had the lowest. Children with patent ductus arteriosus (PDA), a non-severe heart defect, generally performed worse than children with severe CHD and many non-syndromic CA. Children with Klinefelter and Karyotype XXX syndromes started with relatively high attainment rates, but declined considerably at older ages. Under 1% of children with Down Syndrome achieved expected levels at KS1 and KS2.

TABLE 2 | Distribution of sociodemographic characteristics by congenital anomaly status.

	No congenital anomaly, *n* (%)	Any congenital anomaly, *n* (%)	All, *n* (%)
TOTAL	**2,272,742 (100.0)**	**78,847 (100.0)**	**2,351,589 (100.0)**
Year of birth			
2003/04	421,195 (18.5)	14,483 (18.4)	435,678 (18.5)
2004/05	445,480 (19.6)	15,311 (19.4)	460,791 (19.6)
2005/06	459,846 (20.2)	15,920 (20.2)	475,766 (20.2)
2006/07	470,683 (20.7)	16,283 (20.6)	486,966 (20.7)
2007/08	475,538 (20.9)	16,850 (21.4)	492,388 (20.9)
Sex at birth			
Male	1,160,586 (51.1)	47,101 (59.7)	1,207,687 (51.4)
Female	1,112,156 (48.9)	31,746 (40.3)	1,143,902 (48.6)
Gestational age, weeks			
< 32	10,687 (0.5)	1965 (2.5)	12,652 (0.5)
32–38	75,302 (3.3)	4802 (6.1)	80,104 (3.4)
37–41	1,355,335 (59.6)	41,817 (53.0)	1,397,152 (59.4)
42+	69,391 (3.0)	1944 (2.5)	71,335 (3.0)
Missing	762,027 (33.5)	28,319 (35.9)	790,346 (33.6)
Birthweight, grams			
< 2500	96,228 (4.2)	8696 (11.0)	104,924 (4.5)
2500–3999	1,453,552 (64.0)	44,758 (56.8)	1,498,310 (63.7)
4000+	201,694 (8.9)	5890 (7.5)	207,584 (8.8)
Missing	521,268 (22.9)	19,503 (24.7)	540,771 (23.0)
Maternal age at birth, years			
< 20	155,599 (6.8)	5627 (7.1)	161,226 (6.9)
20–29	1,009,114 (44.4)	34,321 (43.5)	1,043,435 (44.4)
30–34	610,174 (26.9)	20,047 (25.4)	630,221 (26.8)
35–39	340,290 (15.0)	11,739 (14.9)	352,029 (15.0)
40+	69,898 (3.1)	2902 (3.7)	72,800 (3.1)
Missing	87,667 (3.9)	4211 (5.3)	91,878 (3.9)
Major ethnic Group			
White	1,611,153 (70.9)	54,834 (69.5)	1,665,987 (70.8)
Black	104,737 (4.6)	3833 (4.9)	108,570 (4.6)
Asian/Chinese	200,567 (8.8)	7765 (9.9)	208,332 (8.9)
Mixed	106,556 (4.7)	3668 (4.7)	110,224 (4.7)
Other	26,943 (1.2)	853 (1.1)	27,796 (1.2)
Unclassified	222,786 (9.8)	7894 (10.0)	230,680 (9.8)
Income Deprivation Affecting Children Index (IDACI) Quintile			
Most Deprived	596,343 (26.2)	21,685 (27.5)	618,028 (26.3)
2nd most deprived	473,994 (20.9)	16,706 (21.2)	490,700 (20.9)

(Continues)

TABLE 2 | (Continued)

	No congenital anomaly, *n* (%)	Any congenital anomaly, *n* (%)	All, *n* (%)
TOTAL	**2,272,742 (100.0)**	**78,847 (100.0)**	**2,351,589 (100.0)**
Middle	417,944 (18.4)	14,267 (18.1)	432,211 (18.4)
2nd least deprived	398,665 (17.5)	13,195 (16.7)	411,860 (17.5)
Least deprived	378,084 (16.6)	12,702 (16.1)	390,786 (16.6)
Missing	7712 (0.3)	292 (0.4)	8004 (0.3)
Free School Meals Eligibility (FSME)			
No	1,859,308 (81.8)	63,082 (80.0)	1,922,390 (81.8)
Yes	413,434 (18.2)	15,765 (20.0)	429,199 (18.2)
Region			
East Midlands	197,047 (8.7)	7853 (10.0)	204,900 (8.7)
East of England	250,776 (11.0)	7096 (9.0)	257,872 (11.0)
London	349,531 (15.4)	9686 (12.3)	359,217 (15.3)
North East	117,115 (5.2)	4045 (5.1)	121,160 (5.2)
North West	295,778 (13.0)	12,263 (15.6)	308,041 (13.1)
South East	357,730 (15.7)	12,175 (15.4)	369,905 (15.7)
South West	218,526 (9.6)	7480 (9.5)	226,006 (9.6)
West Midlands	231,208 (10.2)	10,675 (13.5)	241,883 (10.3)
Yorkshire and The Humber	247,535 (10.9)	7286 (9.2)	254,821 (10.8)
Missing	7496 (0.3)	288 (0.4)	7784 (0.3)

Abbreviations: FSME, Free School Meals Eligibility; IDACI, Income Deprivation Affecting Children Index.

Adjusting for sociodemographic factors, children with CA were less likely than peers to achieve expected levels in English (adjusted risk ratio [aRR] 0.86, 95% confidence interval [CI] 0.85, 0.86 at EYFSP/KS1; aRR 0.87, 95% CI 0.87, 0.88 at KS2); similar results were seen for Maths (Figure 3, Tables S5 and S6). Males were less likely than females to achieve expected levels for each subject and key stage, but gaps narrowed at KS2, with no variation by CA subgroup.

The attainment rates for specific subgroups defined by EUROCAT and alternative codelists differed by ≤1%, with some exceptions in severe CHD (Table S7). Amongst children with CA, attainment rates were highest for isolated, followed by multiple then genetic CA across subjects and ages (Table S8). For the subset of children assessed at all ages, adjusted risk ratios for achieving expected levels, comparing children with and without CA, were closer to the null (Tables S9 and S10).

3.3 | Standardised Scores (z-Scores)

Z-scores were lower by 0.36 (EYFSP), 0.39 (KS1) and 0.16 (KS2) points for children with CA overall compared with peers, with greater variation (Table S11). Differentials were smallest for children with renal anomalies, cleft lip and polydactyly. Excepting Klinefelter and Karyotype XXX syndromes, mean scores for children with CA peaked at KS2, although fewer children had scores.

Estimated mean z-scores generally decreased for females and stayed constant for males over stages; adjustment for sociodemographic factors had little impact (Table 4). The gap between children with and without CA, however, remained largely unchanged for both sexes and subjects, varying ≤0.02 points between EYFSP and KS2. Most of the variation was at age 5 rather than in subsequent rates of change ($variance_{intercept} = 0.64$ [95% CI 0.64, 0.64]; $variance_{slopes} = 0.08$ [95% CI 0.08, 0.08]). Figure 4 shows predicted trajectories stratified by CA and sex, and Figure 5 shows trajectories for selected CA (sexes combined).

4 | Comment

4.1 | Principal Findings

On average, 45.7% of children with CA reached GLD at age 5, with variations by CA subgroup and sex. This was 11.3% fewer than children without CA, a persistent attainment gap observed for English and Maths at all ages. Proportionally more children with CA were not assessed at age 11 compared with their peers (11.3% vs. 2.8%). Adjusting for sociodemographic factors, children with CA were on average 12%–15% less likely than peers to reach expected attainment. Attainment for children with cleft lip, renal, and limb anomalies was generally comparable with peers.

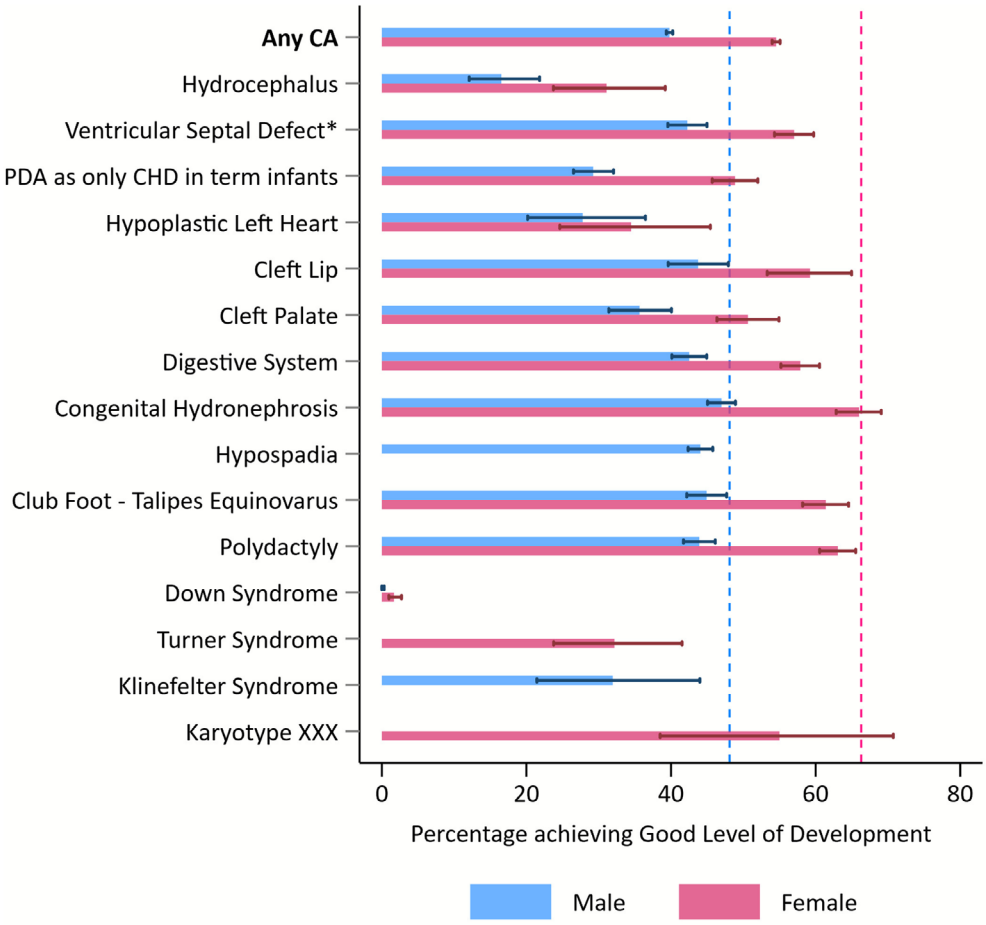


FIGURE 2 | Percentage achieving Good Level of Development at Early Years Foundation Stage Profile, by sex and selected congenital anomaly (CA) subgroups. Whiskers show exact binomial 95% confidence intervals, dashed lines represent values for children without CAs (blue = male; pink = female).

4.2 | Strengths of the Study

HES covers > 96% of births in England and captures 99% of NHS-funded hospital admissions, providing a large sample and many CA subgroups for our study [24]. Linkage to the NPD, covering ~93% of all school-age children [13], provided insights into the academic journey and potential of children with CA. Our findings are therefore representative of a substantial part of the school-age population in England.

4.3 | Limitations of the Data

About 13.8% of total births could not be linked to the NPD, primarily due to the NPD not containing individual-level data on home-schooled children or those in independent schools. Choices are shaped by parents' preferences and circumstances, although some may be due to SEN that cannot be adequately met in state-funded settings. Additional factors include early exits (births to temporarily-resident mothers or emigration), linkage errors or incomplete matching identifiers [25]. Given the diverse factors and comparatively small proportion, we expect the net influence on our results to be modest.

Misclassification of CA status is a limitation. In contrast to CA surveillance registries [26], where cases are notified by care teams and clinically reviewed, case ascertainment using administrative data relies on applying phenotype codelists deterministically to diagnosis and procedure codes, recorded primarily for reimbursement of healthcare provided. Children with CA not requiring inpatient care could be missed (false negatives), whilst the recording of suspected/differential diagnosis codes could generate false positives. Our estimated CA prevalence was 1.5% higher than EUROCAT statistics, and although CA registries could under-ascertain CA, future work should examine this discrepancy. Where available, we have used alternative codelists which yielded more conservative prevalences to minimise the false positive rate. This may bias results toward more severe cases, but could help ascertain the maximum of group differences; for selected CA, attainment rates by alternative methods seemed very similar.

Last, we acknowledge that our study population consisted of potentially 'healthier' children with less severe CA (compared with those not born alive or those who died before school). Whilst our findings may be said to underestimate the 'true' association between CA and educational attainment, our focus was on the

TABLE 3 | Number of children enrolled, % assessed and % who reached expected level of attainment by Key Stage, subject and congenital anomaly (CA) subgroup.

	EYFSP					KS1					KS2				
		English		Maths			English		Maths			English		Maths	
Subgroup	N in census	% assessed	% expected	% assessed	% expected	N in census	% assessed	% expected	% assessed	% expected	N in census	% assessed	% expected	% assessed	% expected
All children	2,351,589	99.3	68.2	99.3	78.1	2,319,460	99.2	66.6	99.1	78.4	2,257,545	96.9	75.9	97.0	77.4
No CA	2,272,742	99.3	68.6	99.3	78.5	2,241,658	99.2	67.0	99.2	78.8	2,181,797	97.2	76.3	97.3	77.8
Any CA	78,847	99.1	56.9	99.1	67.6	77,802	98.9	55.4	98.6	66.8	75,748	88.7	65.3	88.6	66.4
Neural tube defects	275	98.5	50.2	98.5	63.3	272	99.6	54.0	98.9	59.9	266	85.0	59.8	84.6	57.9
Hydrocephalus	390	97.9	31.0	97.9	39.5	386	97.9	29.3	96.9	36.8	374	61.0	36.9	61.0	35.6
Congenital cataract	382	99.0	58.9	99.0	70.9	377	99.5	57.6	99.5	69.2	363	89.3	67.5	90.4	67.2
Congenital Heart Defects (CHD)[a]	11,368	99.2	54.2	99.2	65.3	11,222	98.8	52.3	98.6	63.3	10,925	89.8	62.9	89.7	62.6
Ventricular septal defect[b]	2631	99.2	59.9	99.2	70.7	2597	99.1	57.7	99.0	68.7	2538	91.9	68.4	91.6	68.3
Pulmonary valve stenosis[b]	429	99.1	53.8	99.1	66.0	422	99.3	55.0	99.1	64.5	413	91.3	64.4	91.5	60.8
PDA as only CHD in term infants	2068	98.9	49.4	98.9	60.7	2047	98.5	47.8	98.3	57.4	2001	88.6	61.1	87.9	56.5
Severe CHD[a]	2991	99.3	54.6	99.3	66.2	2946	98.9	51.4	98.6	63.4	2854	88.7	60.4	89.0	62.9
Atrioventricular septal defect	337	99.1	54.6	99.1	65.0	329	99.1	52.0	99.1	61.7	323	88.2	55.7	87.9	58.2
Tetralogy of fallot	528	100.0	55.1	100.0	67.4	517	99.0	51.8	98.8	62.9	501	88.8	61.3	89.6	65.7
Hypoplastic left heart	213	98.1	41.3	98.1	56.3	208	98.1	39.9	98.1	51.0	196	82.7	51.5	80.6	47.4
Respiratory	734	98.8	52.2	98.8	63.6	723	98.6	52.3	98.6	63.2	706	89.0	62.2	89.2	63.2
Cleft lip	854	99.1	61.4	99.1	73.5	837	99.5	61.6	99.3	72.8	817	94.5	70.0	95.3	75.3
Cleft palate	1034	99.8	54.6	99.8	66.1	1023	99.6	53.3	99.4	64.5	1001	91.4	65.3	92.5	65.4
Cleft lip and palate	1086	99.4	54.3	99.4	66.9	1075	99.3	52.3	99.2	67.3	1048	93.0	64.6	94.1	66.6

(Continues)

TABLE 3 | (Continued)

Subgroup	EYFSP					KS1					KS2				
		English		Maths			English		Maths			English		Maths	
	N in census	% assessed	% expected	% assessed	% expected	N in census	% assessed	% expected	% assessed	% expected	N in census	% assessed	% expected	% assessed	% expected
Digestive system[a]	3007	99.3	60.2	99.3	72.0	2977	99.5	59.4	99.4	72.1	2901	93.5	69.8	93.4	71.3
Anorectal malformations	199	99.0	57.8	99.0	68.8	196	99.5	59.2	99.5	69.9	192	91.7	70.8	93.2	69.3
Hirschsprung's disease	454	99.6	59.7	99.6	73.6	448	99.6	58.0	99.3	72.8	437	93.1	69.6	92.7	71.9
Gastroschisis	799	99.1	57.6	99.1	68.1	795	99.2	54.2	99.1	66.7	784	96.0	65.6	96.2	67.0
Unilateral renal agenesis	323	98.1	61.6	98.1	73.7	316	98.4	66.5	98.4	77.2	312	93.3	66.3	93.6	72.8
Congenital hydronephrosis	3532	99.4	64.2	99.4	75.5	3479	99.0	61.3	98.9	77.5	3392	95.7	74.1	95.9	76.4
Hypospadias	3302	99.2	57.8	99.2	71.8	3265	99.2	55.5	99.2	73.8	3195	94.3	69.5	94.5	74.2
Club foot—talipes equinovarus	2213	99.2	63.4	99.2	74.3	2185	99.4	61.0	99.4	73.9	2119	94.6	71.1	94.9	73.0
Polydactyly	3480	99.2	63.0	99.2	74.3	3433	99.1	63.2	99.1	74.2	3345	95.0	72.5	95.0	74.1
Syndactyly	1545	99.7	64.3	99.7	75.2	1527	99.0	62.3	98.8	75.4	1477	95.3	72.5	95.2	74.0
Craniosynostosis	526	99.2	60.5	99.2	73.0	516	99.0	57.6	98.6	69.4	502	91.6	69.1	91.4	68.5
Down syndrome	2134	97.4	2.7	97.4	4.0	2113	95.1	0.7	91.7	0.7	2083	3.2	0.9	2.9	0.7
Turner syndrome	115	100.0	42.6	100.0	47.0	114	100.0	44.7	99.1	38.6	112	80.4	54.5	77.7	40.2
Klinefelter syndrome	72	100.0	40.3	100.0	66.7	72	100.0	26.4	100.0	44.4	69	75.4	27.5	76.8	36.2
Di George Syndrome	136	98.5	8.8	98.5	10.3	135	97.0	c	96.3	c	132	39.4	c	37.1	c
Karyotype XXX	40	97.5	60.0	97.5	65.0	39	100.0	30.8	100.0	48.7	39	87.2	38.5	87.2	35.9

Note: % assessed = percentage of those in census who had an assessment; % expected = percentage of those in census who reached expected level of attainment; c, Suppressed due to small counts.
Abbreviations: CHD, congenital heart defect; EYFSP, Early Years Foundation Stage Profile; GLD, Good Level of Development; KS1, Key Stage 1; KS2, Key Stage 2; PDA, patent ductus arteriosus.
[a]Major group containing other individuals not in the selected CA shown below (indented).
[b]Without co-occurring severe CHD.

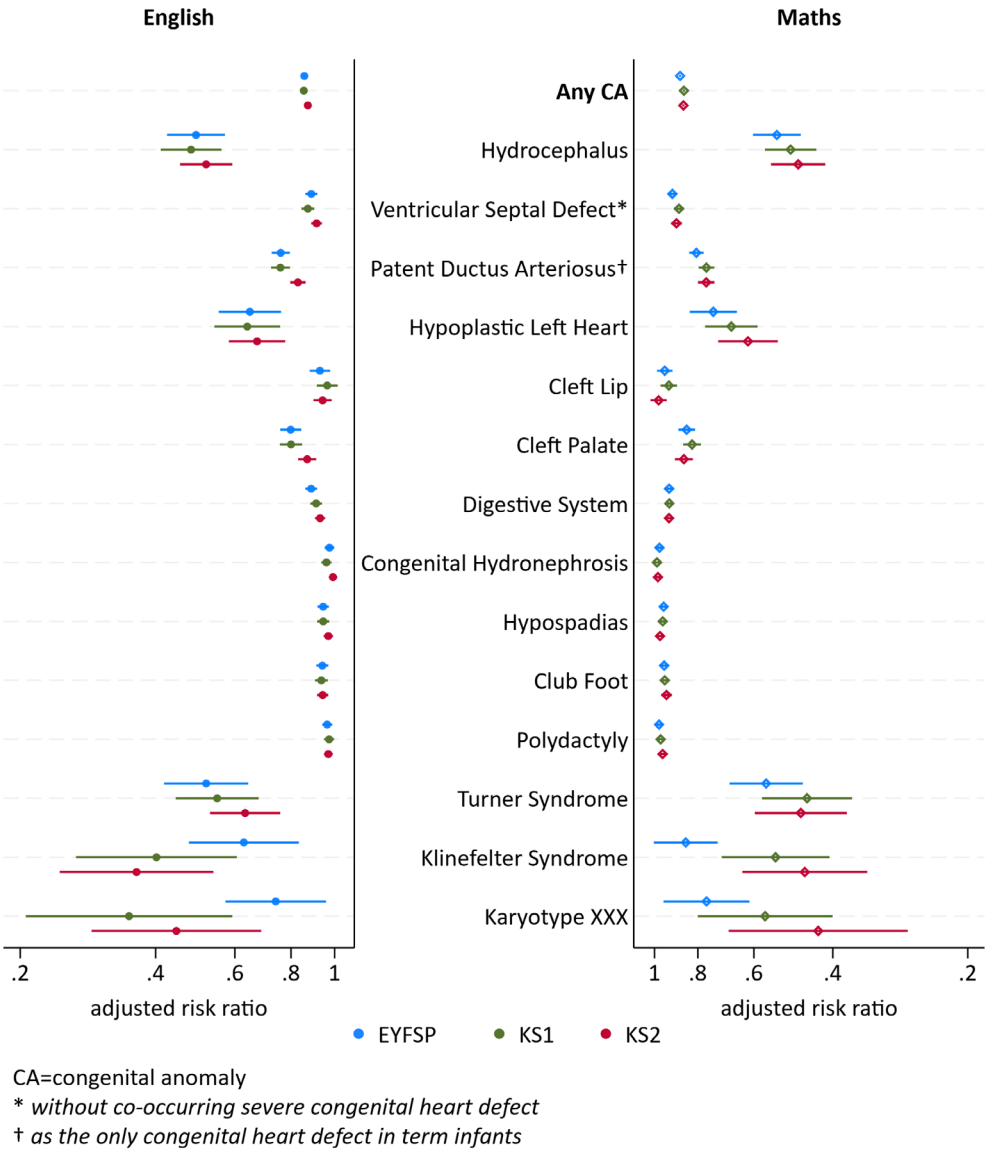


FIGURE 3 | Adjusted risk ratios and 95% confidence intervals for achieving expected levels of attainment in English and Maths, comparing children with selected congenital anomalies (CA) to children without CA (reference), by key stage.

prognosis for children who enter state education to inform parents and services.

4.4 | Interpretation

We aimed to provide evidence on the prognostic attainment trajectories in children with different CA over the first 7 years of their educational journey. Attainment rates peaked at KS2 for English and stayed largely constant for Maths, but the gap between children with CA versus peers remained remarkably consistent at 11% lower throughout. The relatively sharp decrease in proportion of children with CA assessed at KS2 is partially explained by transfers to special schools or disapplication from the National Curriculum after KS1. After controlling for sociodemographic factors, the association between CA and lower attainment was mostly unchanged across key stages. This was also true of children with CA who sat assessments throughout, albeit differences with their peers were more attenuated.

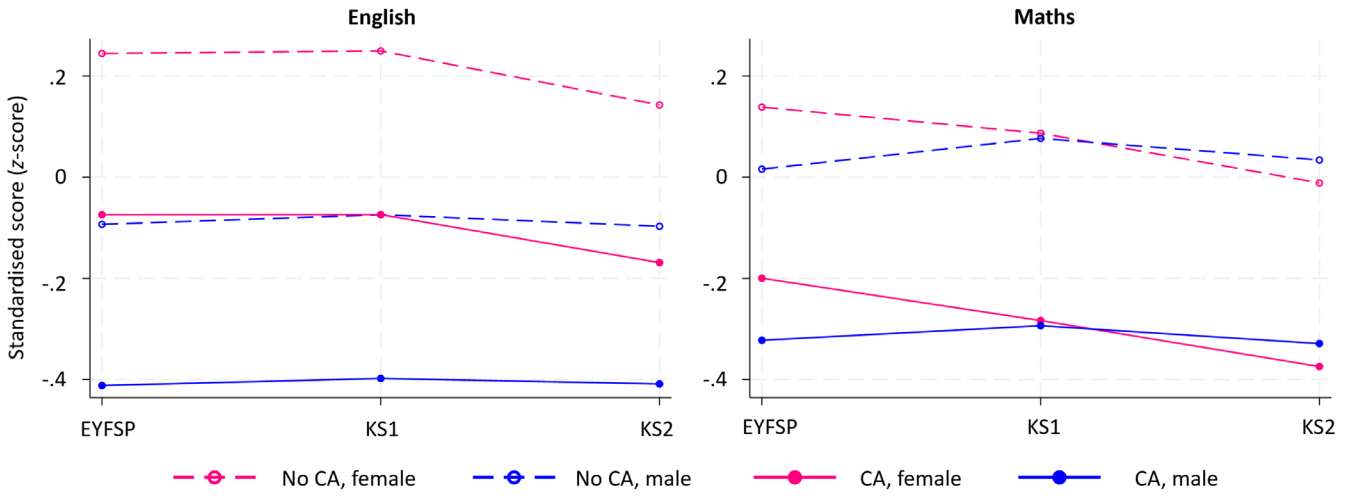
An earlier cohort (1994–2004) from regional English CA registries linked to the NPD found that 72% and 73% of children with isolated CA achieved expected levels in English and Maths at KS2 respectively, 6%–7% fewer compared to peers [9]. Our wider gaps of 11%–12% are chiefly attributable to our overall CA group comprising not only isolated but also potential multiple and syndromic CA, well-established to be associated with lower academic achievement [4], and secondarily to the different denominators used (number of children assessed versus enrolled). Once accounted for, our findings are mutually reinforcing. This study found that the association between sex and attainment in children with CA broadly mirrored that of children without CA, with males performing worse at earlier stages but narrowing the gap with females by KS2 across all CA subgroups, particularly in English.

Our results also align with those of Park et al. on subject z-scores in children reported to the Cleft Registry and Audit Network [3]. Children with cleft lip had the highest scores, followed by those with cleft lip and palate, then cleft palate, a pattern which we

TABLE 4 | Mean differences in standardised English and Maths scores by sex and congenital anomaly (CA) status estimated by linear mixed models using all children with CA and 25% sample of children without CA.

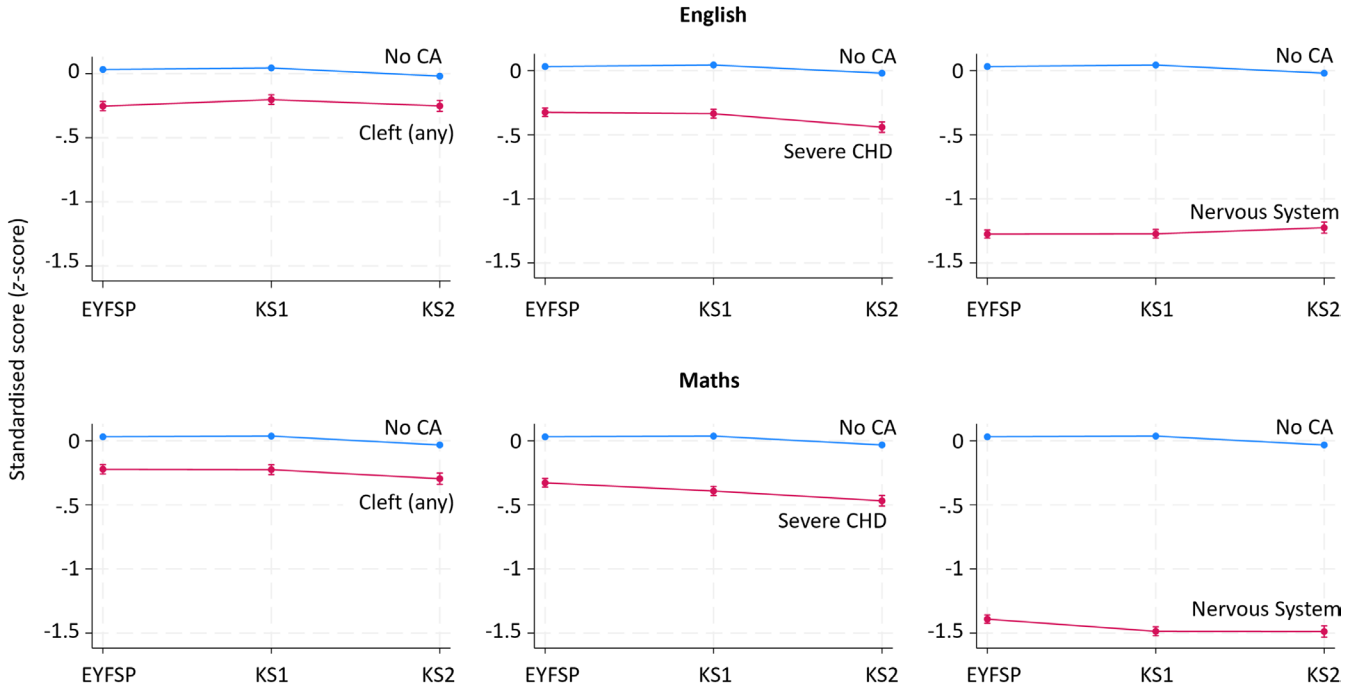
English (total individuals 617,462).		**EYFSP**	**KS1**	**KS2**
Unadjusted				
Female	No CA	0.0 (Reference)	0.01 (0.00, 0.01)	−0.10 (−0.11, −0.10)
	Any CA	−0.33 (−0.34, −0.32)	−0.33 (−0.34, −0.32)	−0.43 (−0.44, −0.42)
Male	No CA	−0.34 (−0.34, −0.33)	−0.32 (−0.32, −0.31)	−0.34 (−0.35, −0.34)
	Any CA	−0.67 (−0.68, −0.66)	−0.65 (−0.66, −0.65)	−0.67 (−0.68, −0.66)
Adjusted for maternal age, ethnicity, IDACI quintile and FSME				
Female	No CA	0.0 (Reference)	0.01 (0.00, 0.01)	−0.10 (−0.11, −0.10)
	Any CA	−0.32 (−0.33, −0.31)	−0.32 (−0.33, −0.31)	−0.41 (−0.42, −0.40)
Male	No CA	−0.34 (−0.34, −0.33)	−0.32 (−0.32, −0.31)	−0.34 (−0.35, −0.34)
	Any CA	−0.66 (−0.66, −0.65)	−0.64 (−0.65, −0.63)	−0.65 (−0.66, −0.64)
Maths (total individuals 617,463)		**EYFSP**	**KS1**	**KS2**
Unadjusted				
Female	No CA	0.0 (Reference)	−0.05 (−0.06, −0.05)	−0.15 (−0.15, −0.15)
	Any CA	−0.35 (−0.36, −0.34)	−0.44 (−0.44, −0.43)	−0.53 (−0.54, −0.52)
Male	No CA	−0.12 (−0.13, −0.12)	−0.06 (−0.07, −0.06)	−0.10 (−0.11, −0.10)
	Any CA	−0.47 (−0.48, −0.46)	−0.44 (−0.45, −0.43)	−0.48 (−0.49, −0.47)
Adjusted for maternal age, ethnicity, IDACI quintile and FSME				
Female	No CA	0.0 (Reference)	−0.05 (−0.06, −0.05)	−0.15 (−0.15, −0.15)
	Any CA	−0.34 (−0.35, −0.33)	−0.42 (−0.43, −0.41)	−0.51 (−0.52, −0.50)
Male	No CA	−0.12 (−0.13, −0.12)	−0.06 (−0.07, −0.06)	−0.11 (−0.11, −0.10)
	Any CA	−0.46 (−0.47, −0.45)	−0.43 (−0.44, −0.42)	−0.47 (−0.48, −0.46)

Abbreviations: CA, congenital anomaly; EYFSP, Early Years Foundation Stage Profile; FSME, Free school meals eligibility; IDACI, Income deprivation affecting children index; KS1, Key Stage 1; KS2, Key Stage 2.



CA=congenital anomaly; EYFSP=Early Years Foundation Stage Profile; FSME=Free School Meals Eligibility; IDACI=Income Deprivation Affecting Children Index; KS1=Key Stage 1; KS2=Key Stage 2

FIGURE 4 | Estimated trajectories of English and Maths mean z-scores by categories of CA status and sex using linear mixed effects regression. Plots constructed using modal values of other adjusted covariates (maternal age: 20–29 years; ethnicity: White; IDACI quintile: 3rd quintile (middle); FSME: No).



CA=congenital anomaly; EYFSP=Early Years Foundation Stage Profile; FSME=Free School Meals Eligibility; IDACI=Income Deprivation Affecting Children Index; KS1=Key Stage 1; KS2=Key Stage 2

FIGURE 5 | Estimated trajectories of mean standardised scores and 95% confidence intervals for English (top row) and Maths (bottom row), comparing children without CA (blue) and children with selected CAs (red). Plotted using average values of adjusted covariates (sex, maternal age, ethnicity, IDACI quintile and FSME).

also observed. They estimated that children with isolated clefts scored up to −0.29 (95% CI −0.36, −0.22) lower than the national average in English, Maths and Science across all ages. Another study of CA cases from a single hospital found that 56%–59% and 62% of children with CA achieved expected attainment in English and Maths respectively at KS1 [4]. Allowing for differences in study settings and coding of outcome metrics, our findings were largely compatible, giving assurance regarding the reliability and reproducibility of our results.

A pooled analysis using linked data from CA registries in Europe showed that children with CA were at higher risk of co-morbidities such as cerebral palsy, seizures, hearing loss and visual impairment between ages 0 and 9 [27]. For example, the prevalence of visual impairment and cerebral palsy was on average 30 and 15 times higher respectively in children with CA than those without CA; nervous system CA such as hydrocephalus were most susceptible to co-morbidities, but even isolated CHD, cleft palate and congenital hydronephrosis showed elevated rates of seizures, epilepsy and cerebral palsy. This may partly explain the unexpected lower attainment seen with some CA subgroups, for example PDA.

The current classification of CA subgroups does not fully capture variations in disease severity, partly due to the lack of data granularity. Additional factors include unidentified, or unidentifiable given available data, underlying learning or cognitive deficits. Whilst a greater proportion of children with CA receive SEN provision compared with their peers [6, 28], decisions on SEN provision are influenced by clinical conditions, sociodemographics, school governance, and parental advocacy [29–31]. The aim of this study was to provide prognostic information for parents, schools and clinicians on education attainment for children with a range of CA types who survived to start school and how they differ from unaffected peers. Future studies could consider the various influences on education attainment including SEN provision, parental and familial factors (e.g., birth order and number of siblings etc.), the home environment, as well as wider drivers of social disadvantage.

5 | Conclusions

Of those enrolled at age 5 in state-funded schools in England, the proportions who continue to age 11 were similar between children with and without CA. Children with CA were however less likely to have assessments, or to reach expected levels of attainment, at every key stage. Notwithstanding some children with CA who performed relatively well throughout, a significant minority did not participate in assessments after age 7. This highlights the need for other ways of assessing progress of children in this group, and for additional support to be provided, starting from an early age. With appropriate intervention, more children can be supported to advance their skills and knowledge for secondary school. Some, but not all, of these advances will be measurable through assessments, and Government should consider how to best evaluate the benefits of early support for children's development.

Author Contributions

R.G., K.H., P.H. and J.T. designed the study. A.C., K.L., V.N., L.G. and A.Z. contributed to coding study variables and data management. J.T.,

J.M. and B.D.S. developed the analytical strategy. J.T. performed the formal analysis and wrote the first draft. All authors interpreted the data and contributed to subsequent drafts. All authors have seen and approved the final version.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

ECHILD data are being made available to accredited researchers for research that benefits the provision of healthcare and education in England. Permission to access the ECHILD database is via application to the ECHILD team (ich.echild@ucl.ac.uk). Data can only be processed within the Office for National Statistics Secure Research Service by researchers who have undergone training through the Research Accreditation Service.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section. **Table S1:** Description of congenital anomaly (CA) subgroups, associated ICD-10 codes, exclusions and published identification methods developed for hospital episode statistics (HES). **Table S2:** Summary of educational outcomes. **Table S3:** Number of children enrolled in primary school and deaths, by age and congenital anomaly (CA) status **Table S4:** Number (%) of children reaching a good level of development (GLD) at EYFSP, by congenital anomaly (CA) subgroup. Subgroups include only individuals with isolated CAs (except for Any CA and chromosomal anomalies). **Table S5:** Adjusted risk ratios for reaching expected levels of a attainment in English, comparing children with and without congenital anomalies (CAs), by key stage and CA subgroup. For each comparison, number of children without CAs = 2,177,654. **Table S6:** Adjusted risk ratios for reaching expected levels of an attainment in Maths, comparing children with and without congenital anomalies (CAs), by key stage and CA subgroup. For each comparison, number of children without CAs = 2,177,654. **Table S7:** Comparison of outcomes from congenital anomaly subgroups defined by EUROCAT and an alternative (Other) codelist. **Table S8:** Percentage of children with structural congenital anomalies (CAs) achieving expected level of a attainment for English and Maths, by key stage and malformation on type. **Table S9:** Adjusted risk ratios for achieving expected levels of a attainment in English, comparing children with congenital anomalies (CAs) and children without, by key stage and CA subgroup, for subset of children assessed at three key stages. For each comparison, number of children without CAs = 2,008,951. **Table S10:** Adjusted risk ratios for achieving expected levels of a attainment in Maths, comparing children with congenital anomalies (CAs) and children without, by key stage and CA subgroup, for subset of children assessed at three key stages. For each comparison, number of children without CAs = 2,009,287. **Table S11:** Distribution on of subject standardised scores for selected congenital anomaly (CA) subgroups by key stage.