Data Bulletin
No. 2

1. Introduction

Why think about SEND data in the midst of the COVID-19 pandemic?

A few examples are emerging of the rapid strides some areas have made to develop vulnerable children databases, to monitor risk and target support during the pandemic. We would love to hear more about these developments, so we can share best practice and potentially learning around some of the information governance challenges.

You may be interested to see a couple of new data tools, developed to help inform local responses to COVID-19. If you know of other useful resources, please let us know so that we can share them through CDC's Data Forum and networks.

> **Office of the Children's Commissioner – Local Vulnerability profiles (COVID-19 resource):**
> https://www.childrenscommissioner.gov.uk/our-work/vulnerable-children/local-vulnerability-profiles/
>
> **These local profiles bring together the latest data on childhood vulnerability, at council level, to help local authorities to understand which groups of children may be most at risk under lockdown. This is a live resource which is updated regularly.**
>
> **New Philanthropy Capital - Data dashboard for charities and funders:**
> https://www.thinknpc.org/resource-hub/update-interactive-covid-19-data-for-charities-and-funders/
>
> **This interactive resource brings together national data on elderly people, health, ethnicity, lone parents, overcrowded housing and other indicators of vulnerability, as well as data on charity density and COVID-19 deaths. Data at local authority and regional level.**

We decided earlier this year that this edition of the Data Bulletin would focus on data linkage. This feels timely, in the context of the pandemic.

The data tools mentioned above provide integrated data: drawing together different datasets, which we can look at side by side, with some estimates of the overlap between them. Data linkage could take us further, showing more clearly which groups, and potentially which individuals, are exposed to multiple risks.

Data linkage involves using a 'unique identifier' such as an NHS number (or matching personal details, such as name, date of birth and postcode) to identify individuals or groups (e.g. children with SEND) across different datasets. This needs to be done securely and consent may be required.[1]

Our first Data Bulletin included an article on data-linking in Middlesbrough, where local services regularly share their data on children and young people with SEND, with key indicators brought together in a joint data dashboard. This has contributed to a clearer understanding of patterns of service use, pressure points, gaps in provision and outcomes, prompting service reviews and changes in commissioning.

This Data Bulletin shares Bedford's experience of data linkage, which they have used to produce a really impressive SEND JSNA; as well as an integrated outcomes framework, developed by the Bedford Parent Carer Forum.

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1. This is a complex area. As a starting point, see ICO advice on the six legal bases for processing data on individuals https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/. CDC recently published legal advice on using NHS numbers on EHC plans https://councilfordisabledchildren.org.uk/sites/default/files/uploads/cdc.NHS_number%20Final_0.pdf

We also have an article on Plymouth's experience of using the 0-25 SEND integrated data dashboard, an online tool launched last year by CDC, which brings together key indicators from many national datasets on children and young people with SEND. The dashboard was recently updated with the addition of an integrated outcomes framework.

A common message emerges clearly from the experience of all these areas: that the process of sharing data across local services involved in supporting children and young people with SEND strengthens joint working and really importantly, helps to make children and young people with SEND "everybody's business".

Special thanks to colleagues in Bedford and Plymouth who were so generous with their time and experience.

We hope you find something of interest here, we would welcome your feedback.

In the next edition of the CDC Data Bulletin, we want to focus on innovations in early years data, including sharing data between health and education and using data to plan ahead effectively. Please get in touch if we could learn from your experience of improving data on children aged 0-5 years, or other SEND data innovations which we could learn from.

Stay safe and well,

Anne Pinney

True Colours Data Champion

Email: CDCdatachampion@ncb.org.uk

2. Improving data on children and young people with SEND in Bedford

Improving data on children and young people with SEND has been central to Bedford's response to a critical local area SEND inspection in early 2018. The great progress they have made has been recognised in their recent reinspection report:

> *"The CCG has worked innovatively with the local authority and NHS Digital to create systems which identify the cohort of children and young people with SEND within local health services. This is supporting accurate and effective sharing of information between services. It is also supporting leaders to identify gaps in services across the area, and to act to address these."* **(Ofsted-CQC reinspection letter, March 2020** https://files.ofsted.gov.uk/v1/file/50150537**)**

Background

At the time of the first inspection, local services were criticised by Ofsted and CQC for lacking evidence of their impact on improving outcomes for children with SEND, across education, health and social care, and for "not collecting evidence of their impact in a holistic or meaningful way". The inspectors also highlighted a lack of shared priorities, partnership working, strategic direction and joint commissioning.

In Bedford's Written Statement of Action, they committed to a wide range of action, overseen by the SEND Improvement Board, chaired by an elected member, with senior representatives from the Borough Council, CCG and Parent Carer Forum. Two joint-funded posts were created: a dedicated SEND Programme Manager and a Joint Development Manager.

Improving data on children with SEND

To inform their new joint commissioning strategy, they wanted to: "identify the current demand for all services – and understand current gaps… and ensure any gaps in data are captured." They also committed to co-producing an outcomes framework in partnership with Bedford PCF (see next article).

There was already a wide range of education and social care data to draw on, which could be improved by sharpening the focus on children with SEND. However, the CCG had struggled to produce data on the SEND-specific cohort, as there was no easy way to identify these children in their data systems.

> *"When I came into the job, I was told there is no health data (specifically on children with SEND), when in fact there is loads - we just weren't joining the dots."* **[Chris Morris, SEND Programme Manager]**

Using NHS numbers as common identifiers

They decided to see if they could use NHS numbers as a common identifier across education, health and social care for all children with SEND, including those on SEN support, to ensure that early intervention would be clearly in focus.

They agreed to limit any new data demands on community health services to a few key priorities: access to services, demand and capacity.

Having located the *Batch and Trace* service in the NHS Digital, the process proved to be quicker and simpler

than anticipated. They produced a flowchart showing how the data would be used and by whom. They reviewed information governance protocols, put in place a data privacy statement and signed a data-sharing framework agreement with NHS Digital.

NHS Digital then carried out a 'batch trace' to extract NHS numbers for all children with SEND. This was done by matching personal details from School Census (forename, surname, date of birth, postcode), shared securely by the local authority.

The first matching process identified NHS numbers for 85% of the SEND cohort. LA officers were able to clarify details (e.g. missed matches due to hyphenated surnames) to achieve matches for over 98%. NHS Digital will rerun the batch trace when updated School Census data becomes available.

Extracting health data on children with SEND

With data-sharing protocols in place, NHS numbers were able to be shared securely with CAMHS and community health services. This allowed them to extract data on children with SEND, on the key questions identified by their Parent-Carer Forum for the SEND JSNA:

- To which services are children with SEND known or previously known?

- What contact have they had with them, face-to-face or other, in the past year?

- What was the average time between referral and being seen?

The resulting JSNA (November 2019, link) brings together an impressive range of data on the SEND cohort.

Learning from the data

Being able to look all together at health, education and social care data on children with SEND was revealing. For example, they found:

> *"The learning disability register may be incomplete. Only 170 young people aged between 14 and 25 are recorded on the learning disability register where data from schools and EHCPs tells us that the number is a lot higher. Of these, only 52 (31%) received an annual health check in 2018-19."*

This has prompted action by each service to increase the take-up of annual health checks for this group. Crucially, sharing their data has contributed to a culture of openness and shared ownership. As the SEND programme manager commented:

> *"If we'd had that conversation a year ago, people would've been making excuses. Now they're saying, how can we help?"*

There was also evidence of delays in accessing SALT, long waits between appointments and some children being discharged, even though this service was specified in their EHC Plan. The data rapidly unlocked additional funding from health and education to deal with the backlog and increase capacity.

Adding a flag for SEND in children's social care records showed that over one third of Children in Need supported by the Borough have SEND and almost half (46%) of children who have had an Early Help Assessment. This reinforces one of the key learning points from this exercise, according to the SEND Programme Manager:

> *"The biggest thing has been 'SEN being everybody's business' – and the data unlocking that."*

Further info

Bedford SEND JSNA (November 2019)
https://bbcdevwebfiles.blob.core.windows.net/webfiles/Social%20Care%20Health%20and%20Community/Bedford%20JSNA/Bedford%20Borough%20SEND%20JSNA%202019.pdf

NHS Digital Batch and Trace Service
https://digital.nhs.uk/services/national-back-office-for-the-personal-demographics-service/demographics-batch-service-bureau

Bedford SEND outcomes framework

Following the critical local area SEND inspection in February 2018, Bedford Parent Carers Forum (PCF) agreed to lead on developing a shared SEND outcomes framework, to help local leaders to better understand the needs and priorities of local children and young people with SEND and their families, and to measure progress in improving outcomes.

They undertook an extensive consultation, engaging with as many families as they could reach using a range of approaches including 14 workshops, coffee mornings, school visits and an online survey, which was based on the UN Convention on the Rights of the Child.

As a result of this process, they developed an overarching outcomes framework, based on five key outcomes:

- Be happy

- Be healthy

- Be ambitious

- Be independent

- Be heard.[2]

The survey is repeated every year and written up in an annual report to local leaders, published at https://www.bbpcf.co.uk/reports. Results also are included in the regular performance reports reviewed by the SEND Improvement Board.

The SEND outcomes framework has been very influential, to the extent that "it has led work (on SEND) over the last few years", as the PCF's chairwoman explained. Importantly, it has resulted in a clear set of shared priorities across local agencies. It sits at the heart of the Bedford Borough Joint SEND Strategy 2019-22 [link].

More broadly, it has contributed to a closer, trusted working relationship between local agencies and the PCF, who are represented on a wide range of strategic boards and actively involved as valued partners.

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2. This model was adapted from the '6 outcomes bees' developed in neighbouring Hertfordshire.

3. Making SEND everybody's business: using the 0-25 multi-agency Data Dashboard in Plymouth

Background

The SEND Data Dashboard [available here] brings together education, health and social care data in an accessible online tool. It aims to help local areas to make better use of the data they already report nationally, through 3 lenses:

- Local profile: understanding local need

- Governance and assurance: 'what did we do and how well are we doing it?'

- Key Performance Indicators (KPIs): 'how do we know we are making a difference?'

The dashboard was recently updated with the addition of an integrated outcomes framework and a set of suggested indicators to collect locally.

Why did Plymouth get involved?

Plymouth City Council played a key role in helping to shape the Data Dashboard and the indicators it includes, as part of a Devon STP-wide pilot in 2018-19, in collaboration with the Council for Disabled Children and NEL Consulting.

As well as wanting to make better use of their own data, Plymouth's Head of SEND hoped that developing an integrated dataset could help them to align the diverse strategic priorities emerging from national policy, such as Transforming Care, the Children and Families Act 2014 and Aiming High.

How are they using it?

> *"We have agreed the big data questions: now let's talk about what it means for us."*
> *(Jo Siney, Head of SEND, Plymouth City Council)*

Plymouth City Council have adopted the SEND Data Dashboard as their key dataset for scrutinising and planning their work on SEND. A data working group (which includes a parent representative with strong statistical skills) identifies important themes emerging from the data, which are discussed at the multi-agency SEND steering group, every other month.

The Data Dashboard's 'local profile – SEN' sheet compares key metrics on the SEN cohort (e.g. % with EHC plans, on SEN support, by type of school, by primary need). This has prompted several 'deep dives' to explore why the local pattern of need differs from the national average and/or statistical neighbours. For example, why is the proportion of children with SEND who have SEMH recorded as their primary need well above average and why is the proportion with MLD below average? The local authority has worked with school SENCOs to improve the consistency of recording primary SEN, including ASD and SLCN.

They are using the data to review how well specialist provision (special schools, resourced provision and units) aligns with the pattern of needs, as reported in School Census data. There has also been work around school

readiness, as the data indicated that difficult transitions to primary school were prompting an upsurge in SEND identification. They are looking at how health visitor data could add to their understanding of these issues.

What difference does it make?

Plymouth's Head of SEND, Jo Siney, is passionate about the potential of the Data Dashboard in getting local partners to focus more clearly on children with SEND:

> *"I can't get over the power of pulling those (Data Dashboard) slides up in front of a group of people: they speak for themselves and you can't get away from it. This is a large group of children and young people… It's been a long journey to accept that SEND is everybody's business." (Jo Siney, Head of SEND)*

Looking at everyone's data together helps to demonstrate how they all have a role to play in improving outcomes for children with SEND. So far, the biggest impact has been on relationships – in other words, how well local agencies work together – but they anticipate that the data will lead to changes in joint commissioning in future.

The fact that the Data Dashboard is a robust national tool which is regularly updated has also been valuable, allowing them to focus their energies on exploring the issues, rather than arguing about which data to use. This is also more efficient:

> *"We're not starting from scratch, as we already have this enormous dataset available and we don't have to construct it every year." (Jo Siney, Head of SEND)*

Although there is a lot of health data in the dashboard (including on mental health services, learning disability, personal health budgets and GP annual health checks data for people with learning disabilities), data on community health services remains an important gap, as many providers are still not reporting in full to the Community Services Data Set [see article in Data Bulletin #1 – link]. Nonetheless, the Data Dashboard has helped to strengthen relationships with health partners, so they are *"still further ahead than we would have been."*

Plymouth is now involved in piloting the delivery of the Data Dashboard using Power BI, a data visualisation tool which can help to communicate messages from the data more clearly.

4. 'Make Every Child Count': New data on children and young people with life-limiting conditions in the UK

Robust new estimates of the number of children and young people (aged 0-19 years) in the UK with life-limiting and life-threatening conditions have been published in a report by Professor Lorna Fraser of the Martin House Research Centre, University of York, launched in April 2020.

Life-limiting conditions are those for which there is no reasonable hope of cure, from which children or young people are ultimately expected to die. Life-threatening conditions, such as cancer, may be cured but treatment may fail. For ease of reference, these are referred to together as 'LLC'.
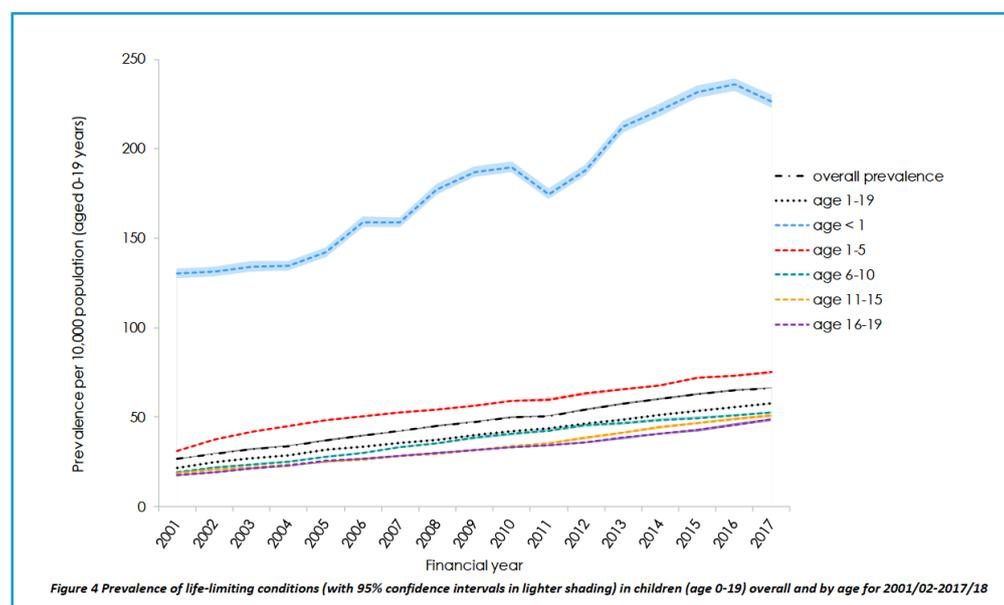
The prevalence of children with a LLC increased markedly over the 17 year study period (2001/01 to 2017/18), attributed in part to improved survival and the earlier recording of these diagnoses.
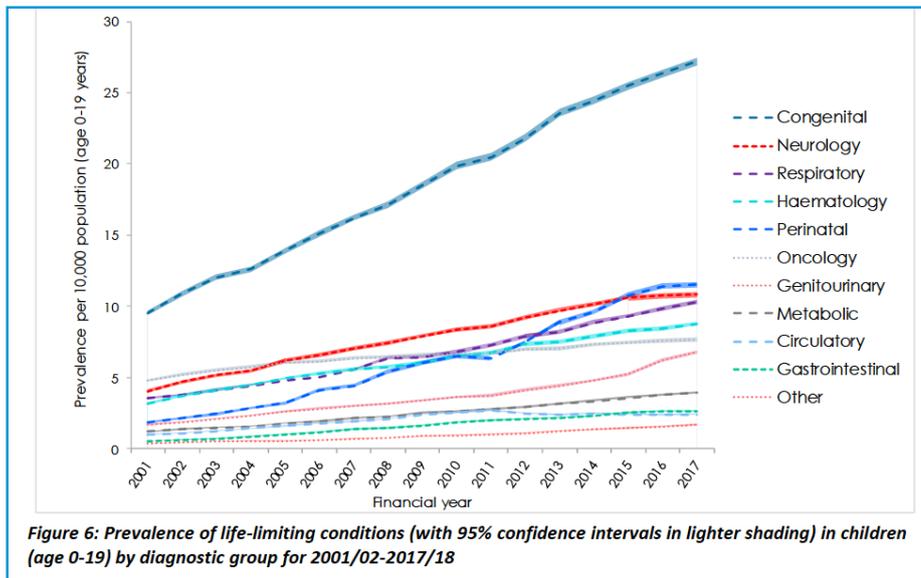
The study used hospital and death certificate data to identify current numbers and prevalence and to estimate future prevalence to 2030, in each UK nation and regions in England. Key findings:

- The number of children with a LLC in England rose from 32,975 in 2001/02 to 86,625 in 2017/18. This equates to an increase in prevalence of 2.6 times, from 26.7 to 66.4 children per 10,000, over the past 17 years.

- Prevalence is expected to continue to grow to between 67.0 and 84.2 per 10,000 children in England, aged 0-19 years, by 2030.

Prevalence of LLCs is highest among:

- the under 1s, at 226.5 infants per 10,000 in 2017/18 (figure 4). The number of deaths is also highest in this age group, which should be seen as a priority for receiving palliative care.

- children with congenital abnormalities, at 27.2 per 10,000 children in 2017/18, more than twice the next most prevalent group, children with neurological disorders (10.8 per 10,000) (figure 5).

Figure 4 Prevalence of life-limiting conditions (with 95% confidence intervals in lighter shading) in children (age 0-19) overall and by age for 2001/02-2017/18

Figure 6: Prevalence of life-limiting conditions (with 95% confidence intervals in lighter shading) in children (age 0-19) by diagnostic group for 2001/02-2017/18

Prevalence was also significantly higher in 2017/18 among:

- boys (72.5 per 10,000) as opposed to girls (60.0 per 10,000)

- children of Pakistani origin (103.9 per 10,000) and lowest among children of Chinese origin (32.0 per 10,000)

- children living in areas of higher deprivation.

Although survival rates improved over the study period (figure 14), 10.4% of these children with a life-limiting condition died during the 17 years of data used by this study, 8.4% before they were age 20. There are a large number of deaths among those under 1 year of age but also among young adults, "highlighting the need for age and developmentally appropriate services".

Figure 14: Proportion of children (age 0-19) with a life-limiting condition who died per year
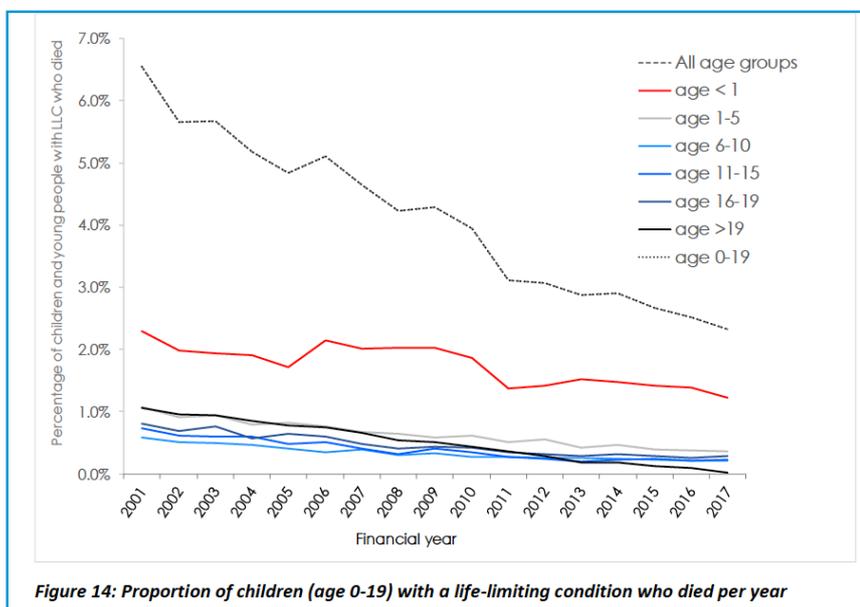
One of the challenges for the study was the lack of any measure of complexity in the health data currently available. In future, point-of-care data reported by paediatricians to the Community Services Data Set (CSDS) on the multi-faceted needs of disabled children and their families should help to fill this gap. For further information on paediatric disability data, mandated for national reporting by community health services, please see CDC Data Bulletin #1 [link] and some helpful resources published on the RCPCH website [link].

Report details: Lorna Fraser et al (2020) *Make Every Child Count: Estimating prevalence of children and young people with life-limiting conditions in the United Kingdom.* Download the report and watch the launch webinar at: https://www.togetherforshortlives.org.uk/resource/make-every-child-count/

5. Data round-up: Recently published SEND data

Explore Education Statistics – new online platform

SEND (and other education data) are now published on a new interactive platform, which allows you to create your own tables by selecting the variables you are most interested in and to download tailored reports. Take a look at: https://www.gov.uk/guidance/explore-education-statistics

Local authority data on children and young people with EHC plans (May 2020)

https://explore-education-statistics.service.gov.uk/find-statistics/education-health-and-care-plans

Headlines from the latest SEN2 data reported by local authorities:

- The total number of children and young people with statements of SEN or EHC plans has increased each year since 2010.There were 390,100 children and young people with EHC plans maintained by local authorities at January 2020, an increase of 36,100 (10%) from 2019.

- The greatest percentage growth last year in EHC plans maintained was for the 20-25 year old age group, up 34% to 25,213, in the year to January 2020.

This data release includes new breakdowns on 12,673 children and young people with EHC plans who are 'Educated Elsewhere'. This broadly means they were not in an education setting, although it includes 1,738 children who are 'awaiting provision and in education.'

In addition, 8,108 young people with EHC plans were NEET (not in education, employment or training) and 2,329 were recorded as 'Other', a category used if an EHC plan will no longer be maintained or is subject to an appeal.

Adding these groups together (and deducting those awaiting provision but in education), we calculate that very concerningly, 21,372 children and young people with EHC plans (5% of all those with EHC plans) were not in an education setting in January 2020.

The table below provides a breakdown of the source data and our calculations – local insights and any comments on our analysis would of course be welcome!

Children and young people with EHC plans 'Educated Elsewhere', NEET or Other England, January 2020 (SEN2 data)	
Permanently excluded	121
Other arrangements by local authority (home ed, soc services, YOIs etc)	3,984
Elective home education	2,983
Other arrangements by parents	618
Awaiting provision - below compulsory school age, not in education	179
Awaiting provision - compulsory school age, not in education	1,260

Awaiting provision - above compulsory school age, not in education	1,790
Awaiting provision - below compulsory school age and in education	131
Awaiting provision - compulsory school age and in education	992
Awaiting provision - above compulsory school age and in education	615
Total of above categories, Educated Elsewhere:	12,673
+ NEET	8108
+ Other (notice to cease maintaining EHC plan, decision under appeal)	2329
= Total (Educated elsewhere + NEET + Other):	23,110
Adjusted total *(deducting 1,738 children awaiting provision & in education)*	21,372
Percentage children & young people with EHC plans not in an educational setting at January 2020 (of total 390,109 CYP with EHC plans)	5%

Link to source data: explore-education-statistics.service.gov.uk/data-tables/permalink/b5bfa517-61e5-4b00-bc87-8daf8a3b4504

Special educational needs: analysis and summary of data sources' (May 2020 update)

https://www.gov.uk/government/publications/sen-analysis-and-summary-of-data-sources

This annual report provides a detailed analysis of the number and characteristics of children and young people with SEND, based on January 2019 School Census data. It includes a really useful table of links to a wide range of data sources on the SEND cohort, including early years, NEET and disability data.

January 2020 School Census data is expected to be published in July.

About the Council for Disabled Children

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector with a membership of over 200 voluntary and community organisations and an active network of practitioners and policy-makers that spans education, health and social care. Their aim is to see a fully-inclusive society where disabled children and young people and those with special educational needs can lead full and happy childhoods and rewarding adult lives. They do this by working with the sector to find out what is and isn't working on the ground and use what they learn to influence policy and improve practice.

CDC hosts the following networks and projects:

Early Years SEND Partnership
IASS Network
Making Ourselves Heard
Special Educational Consortium
Transition Information Network

CDC is proud to be part of the National Children's Bureau (NCB), a leading children's charity working to build a better childhood for every child.