Council for disabled children

Data Bulletin No. 1

1. Introduction: The data challenge

How many disabled children and young people are there in this country, what are their needs and how is this changing over time? How about in your local area?

We should be able to answer these questions.

A lack of robust data on children and young people with special educational needs and disabilities (SEND) makes it harder for local services to plan effectively, to identify gaps in provision and to know how well children and families are faring.

Yet a great deal of data on children and young people with SEND is reported centrally by education, social care and increasingly, community health services. However, it can be difficult to find the right data (for example, to review services for children with autism, across the board) and different definitions, gaps and inconsistencies make it challenging to put together an integrated picture of the needs of disabled children and their families.

Poor data has been highlighted time and again in SEND local area inspections by Ofsted and CQC, as a key factor undermining joint strategic planning and commissioning to improve outcomes for children and young people with SEND.[1]

Local authorities and health commissioners are grappling with rising demand for specialist (‘high needs’) provision, but lack robust data to understand population trends, such as the apparent increase in the number of children with complex disabilities. This prompted the Secretary of State for Education, Damian Hinds, to launch a recent Call for Evidence on funding arrangements for children with complex SEND.[2]

Improving data on disabled children

This data bulletin aims to share learning and encourage progress towards improving data on disabled children. We hope it will interest commissioners, policy makers and others involved in planning and delivering services for disabled children and their families.

Tell us what you think!

This is the first data bulletin from the Council for Disabled Children. We would welcome your feedback to help make it as useful as possible. Please tell us:

- what you would like to learn more about (our next edition will include an in-depth feature on the eRedbook)
- data challenges you are facing, which we can try to find solutions to
- innovative local developments (e.g. data-linking) that others might learn from.

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[1] “Joint commissioning of services across areas is underdeveloped – not seen strong use of needs analysis to ensure local areas can track their SEND population and plan proactively (often SEND has not featured in the joint strategic needs assessment).” Source: Key messages from SEND local area inspections, October 2017 (slide 22)

[2] https://www.gov.uk/government/news/education-secretary-to-work-with-sector-on-special-needs-funding

You can do this by emailing Anne Pinney, CDC's 'data champion' at CDCdatachampion@ncb.org.uk

2. Just launched: CDC's 0-25 multi-agency SEND data dashboard

https://councilfordisabledchildren.org.uk/help-resources/resources/0-25-multi-agency-send-data-dashboard

The Council for Disabled Children is delighted to launch the SEND data dashboard, an online tool to help local commissioners and decision-makers to understand their data, through three different lenses:

- local profile (understanding local need)
- governance and assurance (what did we do and how well are we doing it?)
- qualitative Key Performance Indicators (how do we know we are making a difference?) – currently in development.

The dashboard draws together in one tool a wide range of data (including education, health, social care, benefits and census data) which local areas regularly report on regarding children and young people with SEND.

We hope that it will be a useful resource to inform service reviews, joint strategic planning and commissioning, as well as discussions with parent-carer groups, children's charities and other local partners.

The SEND data dashboard has been developed in partnership with colleagues in health and local government, who helped to select which data to display and key indicators most relevant to SEND commissioning. Useful comparisons are provided where possible and key data are displayed in graphs and charts, which can be selected to download in a report.

We would welcome feedback on how well the tool works and suggestions for further data to include and key performance indicators. Please send to Ryan (rnibloe@ncb.org.uk).

We are grateful to the Department for Education for funding this development and to the NEL Commissioning Support Unit for their expertise in developing the tool.

3. Improvements in health data

Community Services Data Set (CSDS)

NHS Digital collect data on community health services (for people of all ages) via CSDS. This includes a wide range of services and settings, including acute trusts, community trusts, local authorities and independent providers. Currently not all providers submit data, however NHS Digital is working with partners such as Department of Health and Social Care (DHSC) to drive up the number of submitters, with a particular focus on NHS Trusts.

While there are issues around the coverage and quality of the data, NHS Digital has published a range of analyses to show the capabilities of the dataset, including an analysis of children and young people with Special Educational Needs and Disabilities (using paediatric disability data, see below).

From April 2020, these data must be reported using SNOMED-CT, a structured clinical vocabulary used in electronic care records, which is gradually being rolled out across health providers in England.

Paediatric disability data

A special report from the Chief Medical Officer in 2012 recognised the "lack of robust data, particularly at local health service and local authority level, on the numbers, characteristics and circumstances of disabled children, [and that] there is an urgent need to improve the quality of data available to service commissioners."[3]

Great progress has been made since that time, with the development of a consistent approach to recording childhood disabilities, including health conditions, technology dependencies and family-reported issues. This was co-produced by paediatricians, therapists and parent-carers and piloted in Sunderland, before being mandated for national reporting in October 2015.

Health commissioners need to ensure that there are easy-to-use electronic interfaces for clinicians to report the data. Crucially, data should be captured once and used for many purposes. In Sunderland, clinicians use a data capture screen which doubles up as the clinic booking-out slip. They have found that it takes them less than one minute to complete, once familiar with the new system.

Sunderland has been collecting paediatric disability data for several years, leading to many improvements in local services for disabled children and their families. For example, the data informed successful business cases for additional disability paediatricians and therapists, including specialist speech and language therapists on the autism diagnostic team, reducing the time taken to reach a diagnosis.

Data reported by families on barriers to participation led to the establishment of combined paediatric, orthopaedic and physiotherapy postural management clinics that reduce the amount of school time missed by offering a one-stop-shop service rather than multiple different clinic appointments.

To learn more about this rich dataset and the experience of Sunderland, take a look at the videos, articles and other resources published on the RCPCH website: https://www.rcpch.ac.uk/resources/snomed-ct-best-practice-video-resources

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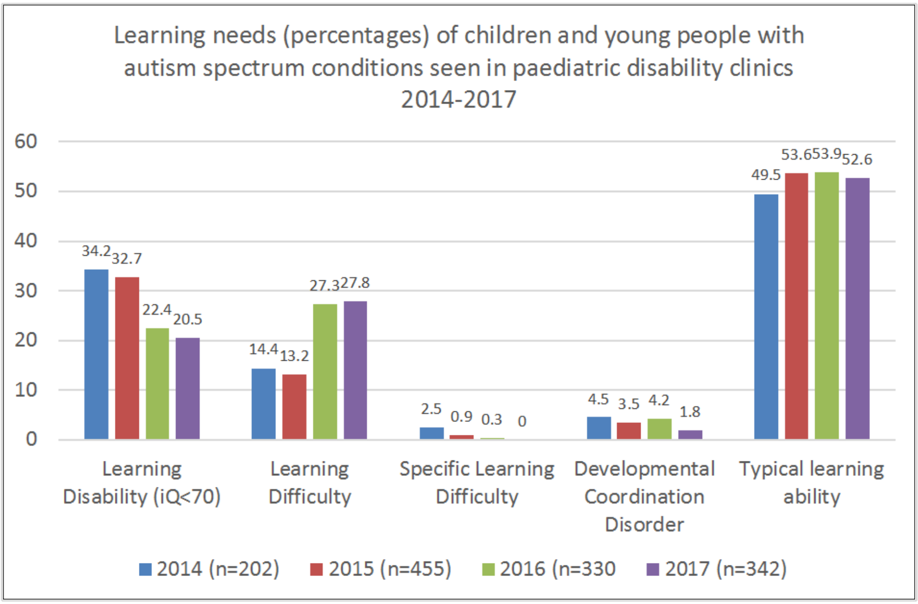
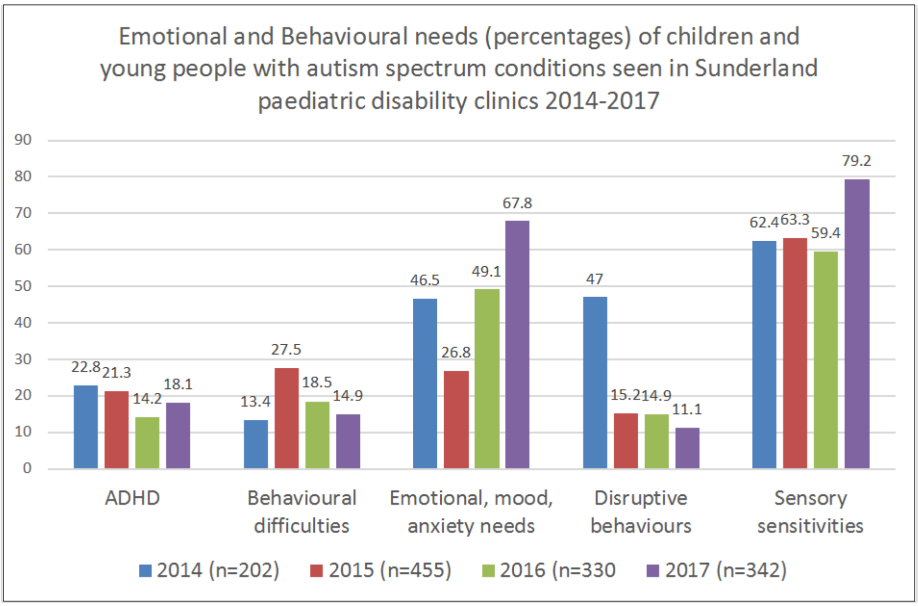
[3] Annual Report of the Chief Medical Officer 2012, Our Children Deserve Better: Prevention Pays (Chapter 9 page 11)

Example charts drawn from Sunderland's paediatric disability data[4]



Learning needs (percentages) of children and young people with autism spectrum conditions seen in paediatric disability clinics 2014-2017



Emotional and Behavioural needs (percentages) of children and young people with autism spectrum conditions seen in Sunderland paediatric disability clinics 2014-2017

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[4] Published by NHS Digital (August 2018) in a SNOMED-CT case study [link]

4. Case study: Data-linking in Middlesbrough

Summary

South Tees Clinical Commissioning Group (CCG) and Middlesbrough Council have worked together to develop data dashboards to monitor the progress of children and young people (aged 0-25 years) with Education, Health and Care (EHC) plans, across education, health and social care. Patterns of service use and gaps in provision for this cohort can now be tracked by each service. Key performance indicators (KPIs) have been developed across education, social care and health which will form the front cover of a joint dashboard. The dashboard will be regularly reviewed by service leaders and used to inform joint strategic planning and commissioning.

Why?

A critical Special Educational Needs and Disabilities (SEND) local area inspection by Ofsted and CQC in 2017 provided the catalyst for change. Like many other areas, Middlesbrough and South Tees CCG were criticised for lacking robust data on children and young people with SEND, limiting their ability to commission effectively or to monitor outcomes.

As part of an ambitious programme of improvement set out in their Written Statement of Action, local leaders committed to developing robust data on children and young people with SEND across education, health and care. They established a 'Data, Quality and Outcomes' group to take this forward, involving each service, as well as parent-carer and head teacher representatives.

How did they do it?

An essential first step was to develop a data-sharing protocol between the local authority and the CCG, with robust information governance arrangements (protecting the use of personal data) in each service.

Data-linking requires a 'unique identifier' so data on the same group of people can be extracted from different sources. After researching the options, they decided to use NHS numbers for this purpose. Advice and permissions were sought from NHS Digital to enable the local authority and health to share data securely, based on 'pseudonymised' data systems. This means that personal data is encrypted so individuals cannot be identified.

Privacy notices and letters were sent to families allowing them to opt out, but only a handful chose to. Then, by matching personal data shared by the local authority on children with EHC plans (e.g. date of birth, postcode), NHS Digital were able to identify the NHS numbers of almost the entire cohort. After testing the system, the data was shared securely. This means that local services – education, health and social care – are now able to extract and analyse data on children and young people with EHC plans. NHS numbers are now requested by the local authority for children with new EHC plans.

How will it be used?

Each service has developed a data dashboard which includes key data on the SEND cohort. For example, the health dashboard includes charts on A&E attendance, elective and non-elective procedures and costs, access to therapies, waiting times and the timeliness of health contributions to the SEND statutory assessment process. This data is monitored by the South Tees (CCG) Children's Team.

The local authority's SEND data booklet also includes an impressive range of data: from early years specialist support and EYFS outcomes, through to progress in education, training and employment beyond key stages 4 and 5. Meaningful comparisons are provided and trends over time are shown where possible. Clear actions are specified (with named contacts, timescales and progress ratings) to take forward issues emerging from the data.

The joint data dashboard of key indicators across all services for children and young people with SEND, including measures from a parent-carer survey, will be produced every quarter and used for regular review, joint strategic planning and commissioning.

What has changed?

"At the time of the inspection, we just didn't understand each other's cohorts."

Already, the shared data have resulted in a clearer, common understanding of patterns of service use, pressure points, gaps and outcomes – influencing service priorities and commissioning.

For example, the local authority has extended early years specialist support services and developed a new delivery model to enable more young children with SEND to be included in mainstream settings.

The new contract for speech and language therapy services (jointly commissioned) has been extended to support young people up to the age of 25 years with a more flexible offer, with similar changes envisaged for other therapy services when their contracts are renewed.

The data helped to inform a successful joint funding proposal for the new Tees Valley Special Free School, to reduce out-of-area placements for children and young people with social, emotional and mental health (SEMH) needs. They are currently looking at how to improve specialist support for secondary school pupils with autism.

The A&E Delivery Board will receive the data which will help future planning. The data highlighted an apparent 'spike' in A&E attendances for young adults with EHC plans, indicating there may be potential difficulties with transitions beyond paediatric care, which the CCG will be investigating further.

In terms of 'softer' impact, colleagues from health, education and social care all reported stronger working relationships, with contacts at the right level in each service. There are now 'SEND champions' in health services, hospitals and nominated health contacts for schools.

The data dashboards are just one aspect of a wider programme of improvement for children and young people with SEND. Great efforts have been made to improve the quality and timeliness of EHC plans, including advice from health and children's social care.

Challenges – and what helped?

Although they were able to make rapid progress (taking only 3-4 months to reach the point where they have useful linked data), challenges remain.

There have been barriers to linking Children and Adolescent Mental Health Service (CAMHS) data and until these are resolved, the CAMHS data covers the full cohort of children and young people, rather than just those with EHC plans.

It has also been harder to link data on the post-16 SEND cohort and the growing number of 19-25 year olds with EHC plans, reflecting weaknesses in SEND data on older teenagers and young adults (also found in national data), following major reforms in the Children and Families Act 2014. Problems with SEND data in a neighbouring council have so far prevented them from implementing the same approach with the CCG. This highlights an important point: data-linking can only be as good as the source data it relies upon.

Familiar problems with incompatible IT systems had to be resolved. Support from their IT and data teams was crucial to progress; the fact that Middlesbrough Council was already investing in developing data dashboards for many services was a great help, as the know-how and capacity were already in place. They were also able to make rapid progress because robust information governance protocols had been developed in a previous exercise to link health and adult social care data.

Invaluable support was provided by the North East Commissioning Support Unit (NECS), in linking health and local authority data. NECS sought permissions to link data across the North East and Cumbria region, which can now be rolled out, dependent on information governance arrangements in place in each Local Authority and the robustness of their data. Several local authorities across the region are working towards this now.

They also have ambitions to develop a multi-agency outcomes framework through the SEND regional group, which will be used for benchmarking progress.

5. Hot off the press: Recent data bulletins on children and young people with SEND

Statements of SEN and EHC Plans, England 2019 (SEN2 data, published May 2019)
https://www.gov.uk/government/statistics/statements-of-sen-and-ehc-plans-england-2019

SEN: an analysis and summary of data sources (wide-ranging data on children and young people with SEND, published May 2019)
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/804374/Special_educational_needs_May_19.pdf

Timpson Review of School Exclusion (includes data tables and a literature review, with detailed analysis on children with SEND, published May 2019)
https://www.gov.uk/government/consultations/school-exclusions-review-call-for-evidence

Coming soon

People with Learning Disabilities in England – Education and Children's Social Care update (2018), to be published soon by Public Health England.

Authoritative analysis of School Census (and some matched children's social care data) on children and young people with MLD, SLD and PMLD: exploring long-term trend in the number/percentage of children with a primary SEN associated with learning disabilities, placements in mainstream or special schools, exclusions, attendance and children's social care status.

Learning Disability profiles (updated December 2018) allowing key data to be downloaded in local area reports, with benchmarking options, available at: https://fingertips.phe.org.uk/profile/learning-disabilities

Special Educational Needs in England, January 2019 (school census data): Expected to be published on 4 July [link]

About the Council for Disabled Children

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector in England, with links to the other UK nations. CDC works to influence national policy that impacts upon disabled children and children with Special Educational Needs (SEN) and their families. The CDC Council is made up of a variety of professional, voluntary and statutory organisations, including disabled young people and parent representatives. CDC's broad based membership and extensive networks of contacts provide a unique overview of current issues. It also enables us to promote collaborative and partnership working among organisations.

CDC hosts the following networks and projects:

- IASS Network
- Independent Advice and Support Programme
- Making Ourselves Heard
- Special Educational Consortium
- Transition Information Network

Council for Disabled Children is hosted by the National Children's Bureau.
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