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POLICY BRIEF

Putting together the data jigsaw: Linking administrative data sets on children with SEND

Learning from local area experience

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Summary

Across England, administrative data is routinely reported by NHS, education and social care services. Multiple policy reviews have advocated for the sharing of data between local agencies to provide richer information to improve policy, service delivery and outcomes.

The aim of this rapid research, carried out between March and July 2023, was to gather evidence from six local areas that link health, education and social care administrative data on children and young people with SEND, or who are working towards this. The research aimed to explore what difference this made, barriers to data linkage and enabling factors.

Semi-structured interviews were conducted online, recorded and analysed thematically. The interviews were anonymous and non-attributable, so findings are reported without naming the local areas, except for in the case studies they shared.

This policy brief also draws on evidence gathered through a Freedom of Information (FOI) request to local authorities (LAs) and Integrated Care Boards (ICBs) across England, between February and April 2023. This is reported in policy briefs 1* and 2* from this project.

The conclusion includes recommendations to policy makers, drawing together suggestions from the local areas involved in this research, solutions discussed at a national policy workshop in May 2023 and recommendations emerging from the FOI analysis.

BACKGROUND

What is data linkage?

Data linkage (or data matching¹) combines data from different sources that relate to the same person to create a new, enhanced data resource (Harron, 2021).

In practical terms, a 'consistent child identifier' like NHS numbers or Unique Pupil Numbers is commonly used to link data on children and young people with SEND, identifying groups (e.g. children with EHC plans or those on SEN support) or individuals in education, health, social care and other data sets. The linked data are de-identified and most often used at cohort level, for SEND data dashboards and strategic planning (Policy Briefs 1 and 2).

Policy context

Government policy broadly supports data sharing to improve outcomes for children and young people, with specific commitments to developing data linkage in the Independent Review on Social Care, the Supporting Families programme and the National Data Strategy.

The SEND review (Her Majesty's Government (HMG), 2022) endorsed 'effective data sharing' as demonstrated by the Supporting Families programme (see below), wanting 'to promote this more widely across the system.' Local and national inclusion dashboards are being developed, including metrics across education, health and care and 'innovative new tools that will facilitate better data sharing across education and health partners' (p. 70).

The Independent Review on Children's Social Care (MacAlister, 2022) recommended action 'to achieve frictionless data sharing' and called for a 'consistent identifier to ensure that data can be easily, quickly and accurately linked' (p. 62). In response, the Department for Education (DfE, 2023) children's social care strategy *Stable homes, built on love, committed to 'improve use of technology and data'*, with a data and digital strategy by the end of 2023.

The DfE report (July 2023) *Improving multi-agency information sharing* cautiously supports using NHS numbers as a consistent child identifier, proposing regional pilots and work to improve the 'interoperability' of data systems and to build practitioners' confidence in sharing information.

* Policy briefs 1 and 2, published by the University of Sunderland: Martin-Denham, S., Scott, N., Horridge, K. and Pinney, A. (2023) *Putting together the data jigsaw: The extent of the linking of administrative datasets on children by local authorities in England. Responses to a Freedom of Information request*; and Scott, N., Martin-Denham, S., Horridge, K. and Pinney, A. (2024) *Putting together the data jigsaw: The extent of the linking of administrative datasets on children by Integrated Care Boards in England. Responses to a Freedom of Information request*. ¹ Definitions: the terms 'data linkage' and 'data matching' can be used interchangeably. Data sharing is a looser concept, ranging from sharing service level data that does not identify individuals to sharing individual records e.g. between health providers or for safeguarding purposes.

Much local progress towards sharing children's data has been driven by the Supporting Families programme, which introduced a payment-by-results model based on a cross-cutting outcomes framework. This programme has 'always promoted the use of data as an enabler to help local services to identify, understand and better support children and families at the right time, to prevent them reaching crisis point' (Department of Levelling Up, Housing and Communities (DLUHC), 2023, p.16).

These policy developments are against the backdrop of a cross-Government commitment in the National Data Strategy (Department for Science, Innovation and Technology (DSIT) and Department for Digital Culture, Media and Sport (DDCM&S), 2020) to 'drive the use of the Digital Economy Act 2017 as well as addressing barriers to data sharing' (6.2.1). The National Data Strategy commits 'to improve data linkage methods, application and skill sets across government' (4.2.1), implementing the recommendations of the 'Joined-up data in government' report (ONS, 2020), which called for 'a joined-up approach to ensure that data linkage is at the heart of improvements to official statistics.'

To what extent are local areas linking data on children and young people with SEND?

The first policy brief in this series, based on an FOI to local authorities (LA) across England, showed that nearly three-quarters (73.6%) already link education and care data, but just under one quarter (24.2%) link their data with health datasets.

A parallel FOI to ICBs reported in the second policy brief, showed that 57.9% of ICBs link health data sets on children and young people, but only 15.8% of ICBs link health and LA data sets.

These findings are consistent with the latest annual data survey for the Supporting Families programme (DLUHC, 2023) which found 'Internal local authority data (such as children's social care, education, and youth offending data) continue to be the most often shared. There continues to be low levels of data sharing with health partners at a local level' (p. 17).

FINDINGS FROM THE LOCAL AREA RESEARCH

Why link data on children and young people with SEND?

Interviews with six local areas explored how they were using their linked data on children and young people with SEND and what difference it made. Six high level themes emerged, illustrated below with examples and case studies from the local areas.

1 Informing Joint Strategic Needs Assessments, joint commissioning and workforce planning



Case study 1: Investing in Speech and Language Therapy services

In Bedford Borough, using NHS numbers to identify children with EHC plans in health data provided evidence (consistent with family feedback) of delays in accessing speech and language therapy, long waits between appointments and some children being discharged, even though this service was specified in their EHC plan. This unlocked additional joint funding from health and education to deal with the backlog and increase capacity.

In Middlesbrough², being able to identify children and young people with EHC plans in regularly-reported health data, led them to develop a new contract for speech and language therapy services (SLT, jointly commissioned) to extend access to SLT up to the age of 25 years, with a more flexible and personalised offer.

² Middlesbrough was not involved in this research but kindly updated a case study previously written by the author, published in CDC's SEND Data Bulletin #1.

2 Understanding patterns of service use, pressure points and gaps in provision

One area involved in this research uses their linked data to help with sufficiency planning for children and young people requiring specialist school provision, also using their live data dashboard to find placements in resourced provision rapidly. Another area used their linked data to inform a successful bid for a new specialist school to reduce out-of-area placements of young people with social, emotional and mental health needs. Further examples are provided in case study 2.



Case study 2: Understanding patterns of service use in Bedford Borough

Being able to identify children and young people with SEND in health data shone a light on which services they were accessing, showing that more children with SEND were accessing the core CAMHS service than the Neurodevelopmental Team within CAMHS. This helped to reframe the discussions around SEND in mental health, demonstrating the extent to which SEND needs to be 'everyone's business.' Over 90% of the local CAMHS workforce have now had SEND training, as well as training on how to input into an EHC plan.

The data also showed that over 50% of children with SEND were on the caseload of community paediatricians, even though many no longer had a clinical need and could appropriately be discharged. This also helped to build a business case for Nurse Prescribers, who can undertake medication reviews, lightening the load on paediatricians.

3 Informing early intervention strategies

One area in this research provides regular data reports to their behaviour, inclusion and well-being panel, informing strategies to reduce exclusions of children and young people with SEND and to support the success of mainstream placements. Another area has put in place data-sharing agreements that will enable them to use health data to plan ahead for when young children with complex disabilities are ready to start nursery or primary school [Case study 3].



Case study 3: Planning ahead for infants with complex disabilities in Hartlepool

Hartlepool Borough Council has created an integrated 0-19 service for health visiting, school nursing and Early Help. Teams are co-located with health visitors and school nurses using SystemOne and Early Help workers using the Early Help Module; NHS numbers are used on both systems as a consistent identifier.

Health bodies have a duty (Children and Families Act 2014, s.23) to inform the local authority if they think a pre-school child has SEN or a disability. To ensure this routinely happens in Hartlepool, data-sharing agreements have been put in place to allow data to be shared on babies identified with disability, antenatally or after birth.

This will enable a proactive approach to supporting families of children with complex disabilities and planning ahead to ensure that specialist support is in place when the time is right for the child to start at nursery or primary school.

"It's small numbers of children, so we should be able to identify them, we should be able to be planning for them coming into the early years settings and school setting, so that resources are allocated early."

(Health Improvement Practitioner)

4 Informing targeted responses

Linked data can be used to inform targeted interventions for vulnerable groups and individuals; 45% of ICBs and 53% of LAs responding to the FOIs reported that this was one way in which they used linked data.³ The best example from the local area research is the live data dashboard developed by Bradford Council, which has become a key tool for operational managers [Case Study 4].



Case study 4: Monitoring and supporting vulnerable young people in Bradford

Bradford Council have developed a live data dashboard, refreshed daily, which includes a wide range of local authority data on children and young people.

A 'vulnerable' tab brings together key data on children and young people with EHC plans or on SEND support who are known to social care or the youth offending team, as well as those home educated, not in education, employment or training or missing from education.

NHS numbers are used as consistent identifiers across the LA data, as they provide the most universal coverage. Data linkage enables a continuous focus on children and young people with multiple vulnerabilities, including:

- the 'Aurora cohort' – those with an EHC plan who have a child protection plan (CPP) and are at risk of exploitation
- children with an EHC plan who are also known to social care (CPP or Child in Need)
- children with an EHC plan who are missing education.

The data dashboard has become a key tool for operational managers, helping them to monitor changes in vulnerable cohorts and allowing those with approved access to drill down to individual level. This proved invaluable during the pandemic for keeping track of vulnerable children and young people.

The data is regularly reviewed by Bradford's Complex and Vulnerable Panel and a Complex and Vulnerable casework team that has been established to ensure that those at the greatest degree of risk have the enhanced support they need.

The data dashboard is continually reviewed and further developed, also being used to inform key strategic decision making for children and young people across the district.

³ 17/38 ICBs (44.7%) reported using linked data for targeted interventions, compared to 48/91 (52.75%) local authorities responding to the FOIs, as reported in Policy Briefings 1 and 2 from this project.

5 Understanding impact and enabling a 'whole system' response

A clear theme to emerge from the interviews with local areas was their improved ability to monitor outcomes for children and young people with SEND in a more meaningful, cross-cutting way (and importantly, being able to demonstrate this to local area inspectors⁴). As one local respondent explained *"It's about impact, but it's also around how do we triangulate the information that we are capturing as a system to make this a system response?"*

Several had co-produced outcomes frameworks with young people and families and being able to identify children and young people with SEND in health, social care, youth justice and other data helped them to evaluate how well they measured up across the different domains.⁵

6 Developing a shared understanding of the needs of children and young people with SEND and shared ownership of this cohort

Lastly, a key theme to emerge from interviews with local areas was the gains in partnership working that have grown out of working together to link their data and then regularly meeting to discuss multi-agency data reports on the SEND cohort. As well as building relationships between teams, sharing data involves being open about challenges and enables others to become part of the solution.

For example, one area triangulated their data on young people with learning disabilities. 170 young people aged 14 to 25 were recorded on the (social care) learning disability register, but education data showed a much higher number of young people with learning disabilities (Moderate Learning Difficulties, Severe Learning Difficulties or Profound and Multiple Learning Difficulties in School Census terms). Meanwhile, the health data showed that only 52 young people with learning disabilities had received an annual health check. This prompted action by each service to increase the take-up of annual health checks for these young people. 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?"*

Barriers and enablers

The interviews with local areas also explored barriers to linking data on children and young people with SEND and enabling factors. Barriers are summarised first under five key themes.

1 Health data

The most frequently-mentioned barriers by local authority respondents were in relation to health data, where data linkage tended to be limited to cohort level data (typically only on children and young people with EHC plans) shared at regular intervals.

Barriers included:

- lack of knowledge of health data by LA partners, exacerbated by a lack of national clarity around what health data should ideally be included in a SEND data dashboard
- perceived unwillingness of health partners to share data, beyond occasional cohort-level reports on agreed priorities. Two local authority respondents, both with experience of working in health, described a tendency to 'over-cautiousness' or 'risk aversion' in relation to sharing health data
- needing to develop data-sharing agreements with multiple health partners, although it was hoped ICS structures might enable a more consistent, strategic approach in future. However, the transition to ICS was frustrating progress in two areas, as data priorities had to be negotiated anew
- lack of leverage to get health provider collaboratives to share data on children and young people with EHC plans, unless this was embedded in their contracts
- differing boundaries and age ranges between local authority and health data sets.

⁴ Ofsted and CQC Area SEND inspection framework. Annex A seeks information on the local area partnership's outcomes measures for children and young people (2.6). Local area partners are also judged on the extent to which they have 'an accurate, shared understanding of the needs of children and young people in their area' (evaluation schedule, paras. 32 and 57) taking into account the extent to which 'leaders share information across education, care and health services so they can learn from different perspectives and approaches.' ⁵ Described in more detail in CDC's SEND data bulletins 2 & 3, Bedford and Bradford case studies.

2 Information Governance

Information governance (IG) requirements were the second most often mentioned barrier. While there are necessary and appropriate restrictions on sharing data (in particular, children's personal data and health data), there are also clear legal bases for doing so.⁶

A common message from local areas was that significant time needs to be invested to work through IG requirements with all parties, including to put in place data-sharing agreements (DSAs) and data protection impact assessments (DPIAs). Different Data Protection Officers in health and local government were said to offer inconsistent advice at times, on what was possible and appropriate.

3 Data and digital challenges

Five of the six areas in this research highlighted data and digital challenges. These involved:

- A lack of consistent identifier across different datasets, with NHS numbers as the preferred solution in the majority of these areas
- Data quality issues which came to light as a result of wanting to link their data, for example, finding gaps in data-reporting and inconsistent use of SEND categories
- Incompatible IT systems within local authorities (principally between education and social care) and within health (with different health services sometimes using different systems)
- A lack of digital maturity, with several mentions of data stored on spreadsheets needing to be collated manually, at the start of their data linkage journey.

4 Cultural challenges

Half of the case study areas referred to a significant cultural change that had arisen from sharing data on children with SEND, acknowledging that they had previously been 'working in silos' and not 'sharing ownership' of children with SEND. Two areas made the point that sharing data is harder when there are significant backlogs in demand, notably around access to therapy services at present; in this context, fear of scrutiny may be a barrier to progress.

5 Resources, local capacity

Lastly, half of the areas identified resources as a barrier to progress. Partnership working, improving data and digital capability and navigating complex information governance requirements all requires considerable investment of time and resource.

Equally, a failure to invest can lead to inefficient processes being perpetuated. Notably, several areas mentioned that data on children with EHC plans (new plans, ceased plans and in some areas, primary SEN) had to be manually entered on to health systems periodically.

Enablers

Local areas identified four enabling factors which helped them to make progress with SEND data linkage.

1 Senior strategic commitment, governance and scrutiny

Senior strategic commitment emerged, perhaps unsurprisingly, as the main factor influencing progress with SEND data linkage. Without this, as one local respondent said, it gets put in the 'too hard to do box'.

For most areas involved in this research, needing to work together to produce a Written Statement of Action following a negative local area inspection outcome, was the catalyst to join up their data on children and young people with SEND.

Progress was made in a variety of ways, recruiting dedicated posts or small teams with a mandate to develop integrated data on the SEND cohort; or establishing a data working group with multi-agency representation to take forward the process.

Several areas emphasised the importance of 'strong, mature partnerships' and a governance structure that 'owns' the data, bringing together Directors or Assistant Directors to oversee progress and to 'trouble shoot' in the developmental phase, which tended to take a year or more.

Three of the areas who had made good progress with SEND data linkage emphasised the importance of using the data, giving it due time and attention, so that its value is recognised. Typically, three levels of governance were described:

⁶ This is a complex area, clearly explained in ICO guidance <https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/data-sharing/data-sharing-a-code-of-practice/data-sharing-and-children/>

- A senior multi-agency board or panel who scrutinise 'KPIs' (key performance indicators) at regular intervals
- A multi-agency management/operational level forum OR a variety of smaller groups e.g. an inclusion and well-being board, who receive more detailed data reports regularly
- A data working group or 'task and finish' groups involving all relevant services, to carry out more in-depth investigations using the data, responding to questions raised by managers, strategic leaders and parent-carer representatives.

Parent-carer voice was integral at least one of these levels, helping to triangulate the data with the experiences of local families and influencing the focus of 'deep dives' to explore issues further.

2 Integrated teams, systems and strong working relationships

The second key theme to emerge in exploring enabling factors with local areas, was how much easier data linkage became in the context of integrated services, teams and data systems. For example, one area merged its health visiting and school nursing team with the Early Help service (Case Study 3); another developed a shared information system across education and social care; another adopted NHS numbers as a consistent identifier for children and young people in their own data systems.

Less formally, two smaller local authority areas with less transient populations commented on the importance of strong working relationships and how they felt able to pick up the phone to colleagues in other agencies to resolve difficulties, because they knew them well.

3 Health expertise

Many of the barriers highlighted related specifically to health data on children and young people with SEND. Enabling factors in this respect were:

- in-depth knowledge of the NHS, commissioning, contract management and health data, with the senior officers who led the development of SEND data linkage in two of the case study areas having previously worked in health or in a joint-funded role;
- support from an NHS commissioning support unit, bringing expertise in health and information governance, as well as secure data-processing capability.

Another suggestion from a local area, also made in the national policy workshop organised as part of this project, was to use the secure data-warehousing and data-processing capability developed within parts of the NHS to link local authority and health data on children and young people with SEND.

4 Local data linkage experience and capability

A final enabling factor, mentioned in two local areas, was prior experience of data linkage, for example in adult health and social care. This helped in at least two ways: partners understood the concept and the potential benefits; and 'in-house' capability and expertise were already in place to help with the technical and information governance challenges. With the Health and Care Act 2022 (Part 2) making it easier to share information between health and adult social care, this may be expected to grow in future.

What would help? Research and policy suggestions from local areas

Lastly, the local area interviews invited suggestions of how national policy and research could help them to make progress with SEND data linkage, summarised below.

1. Clear national expectations of the key SEND indicators that local services should be reporting; in particular, clearer expectations around health indicators, to be prioritised for reporting by provider collaboratives.
2. A clear national mandate to link data on children and young people with SEND, with clear expectations on data-sharing between health and local authority services.
3. Model data-sharing agreements (and other IG requirements) which local areas could tailor to their circumstances, to help them to make progress efficiently.
4. Funds to develop local capacity to link children's data to 'pump prime' progress in linking data on children and young people with SEND, and to share learning.
5. Opportunities to share learning and experience of SEND data linkage and useful resources. For example, how can local areas best use their data to demonstrate system-wide impact for children and young people with SEND?
6. A joined-up approach from central Government and from the inspectorates, so that local areas can be confident that their investment in developing multi-agency data dashboards and outcomes frameworks will meet expectations.

Discussion

Data linkage can enable local areas to develop a robust, integrated picture of the needs of children and young people in their area and to plan ahead in a joined-up way, in line with the aspirations of the Children and Families Act 2014 (sections 25 & 26) informing JSNAs, joint commissioning and workforce

planning. The areas involved in this research also valued data linkage for improving their understanding pressure points and gaps in provision; informing early intervention strategies and targeted interventions; understanding impact across the system, strengthening partnership working and shared ownership of SEND.

At the same time, they described significant barriers, particularly to linking health and local authority data. This reflects the FOI findings (described in Policy Briefs 1 and 2): only 24% of LAs and 16% of ICBs currently link local authority and health data on children and young people; while around three-quarters of local authorities (74%) and nearly three-fifths of ICBs (58%) link internal data sets on children and young people.

This rapid research provides some evidence on barriers to linking local authority and health data on children and young people. The SEND Review (HMG, 2022) pledged to facilitate better data sharing across education and health partners, and our research suggests that this will remain difficult until the barriers to sharing health and local authority data on children and young people are addressed. Participants in the national policy workshop organised as part of this project argued that this would probably require a change in primary legislation.

This will also be important to enable local areas to develop robust data on trends in prevalence (as expected in the SEND Review, p.30 & 76), as paediatric disability data in the Community Services Data Set⁷ is arguably the key data set for understanding trends in childhood disability, providing a much fuller picture than SEND primary needs data (Pinney A., 2017, p.18-19).

The focus of this research was on SEND data linkage but in reality, data linkage is about understanding children and families' multi-faceted needs, not just about one service or one cohort. Improving data and digital capability in SEND urgently requires the same policy attention and focus as in children's social care (where approaches to sharing information with health are being actively explored⁸); but ideally these should be taken forward together, to make the most of the investment of time, expertise and digital capability and because children and young people's lives do not fit into service silos.

⁷ Mandated since November 2015 but reporting remains patchy in some areas. See Horridge K. (2018) *SNOMED CT Case Study*, NHS Digital.

⁸ Pilots announced in DfE (2023) *Improving multi-agency information sharing*, p.119-120

National policy recommendations

This is the third publication from a UKRI Policy Support Fund project led by the University of Sunderland, which involved an FOI to all local authorities and ICBs in England, a national policy workshop and rapid research in six areas. We conclude by reiterating the policy recommendations made in our first two briefings, which are strikingly consistent with the suggestions made by the local areas involved in this research.

We recommend a national strategy to tackle the barriers to linking children and young people's data at the local level, particularly between local authority and health services, including:

- 1 A consistent unique identifier to support efficient and effective data-sharing and linkage
- 2 Opportunities for LAs and health partners to share learning on how they have successfully linked data to improve outcomes for children
- 3 Best practice guidance and templates to make it easier for LAs and health partners to develop data-sharing protocols and processes
- 4 A grants programme to stimulate and evaluate progress
- 5 A consistent data capture interface for clinicians to use at all points of health care to improve reporting of paediatric disability data in the Children's Community Services Data Set
- 6 Data capture at all points of care and services across agencies needs to be in place, to ensure that quality data are available to link.

Although there are many recent policy commitments to improving data sharing and data linkage, a joined-up approach is urgently needed within Government, including forging links between current SEND and children's social care data, digital and information-sharing developments.

Limitations and future research

This rapid research involved online interviews lasting up to 45 minutes with six local areas. Local areas were identified through a request to health and local government SEND leads and commissioners by the Council for Disabled Children on behalf of the author; 'warm' contacts from prior research by the author; and new approaches based on FOI responses.

An important limitation is that this was not a representative sample of local areas. All respondents were currently in local authority roles. Half of the areas responding were unitary authorities, half were metropolitan district councils; no county councils or London boroughs were involved. Research with a wider range of respondents, in particular with better health representation, may have yielded different insights. More in-depth research is recommended to explore barriers and solutions, especially from the health perspective.

Lastly, we were only able to transcribe five of the six interviews as one respondent did not wish their interview to be recorded; detailed notes were taken which were included in the thematic analysis.

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