OPINION

From backlog to blind spots: improving data visibility across autism and ADHD pathways in England

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Summary All-age autism and attention-deficit hyperactivity disorder pathway reform in England is often framed around waiting lists and capacity. However, backlog data alone cannot show how people move through referral, triage, assessment, support and follow-up, or where inequities and unmet need are hidden. Current data also struggle to distinguish confirmed diagnosis, suspected diagnosis, disclosure, self-identification and co-occurring needs. This creates pathway blindness: systems can see pressure, but not flow, fairness or diagnostic visibility. We argue that reform should begin with structured system mapping, agreed definitions and a realistic minimum data-set before dashboards or predictive analytics are used to guide service change.

Keywords Autism; ADHD; neurodevelopmental pathways; system mapping; health inequalities.

Backlog is visible; pathway flow is not

Autism and attention-deficit hyperactivity disorder (ADHD) assessment pathways are under intense pressure in England. Recent national reporting shows more than 200 000 people waiting for autism assessment and large numbers waiting for ADHD assessment.[1,2] The policy response has understandably focused on capacity, procurement and waiting list reduction. These are necessary, but they are insufficient. Systems can count pressure without understanding the pathway dynamics that produce it.

This article addresses all-age autism and ADHD pathways, rather than treating neurodevelopmental pathways as a homogeneous category. Autism and ADHD share challenges around demand, waiting and fragmented pathway visibility, but their pathways are not interchangeable. Autism assessment guidance describes stages from identification and referral through screening, pre-assessment support, assessment and post-assessment support, whereas ADHD pathways may additionally include medication initiation, titration, monitoring and prescribing or shared care arrangements.[3,4] Differences also arise by age: transition between children and young people's (CYP's) and adult services is a recognised potential gap in autism pathways.[3]

The organisational architecture also differs between CYP and adults. CYP ADHD assessment is often delivered through community paediatric services, although mental health services may also be involved; adult ADHD services are more commonly delivered within mental health services.[5] Primary care, independent providers and Right to Choose provision may create additional interfaces. Autism assessment arrangements are more heterogeneous and may involve child development, neurodevelopmental, mental health or specialist autism services, depending on age and local configuration.[3] Consequently, a single pathway model should not be assumed to apply across diagnoses or age groups.

The information architecture reflects this fragmentation. Current national autism waiting time statistics include activity reported through the Mental Health Services Data Set (MHSDS), but community paediatric autism assessment activity reported through the Community Services Data Set (CSDS) is not yet included because autism assessment activity cannot currently be identified consistently within CSDS.[1] For ADHD, national management information draws on multiple sources, including MHSDS and community paediatrics waiting list data. However, current reporting cannot identify everyone waiting specifically for an ADHD assessment; does not fully capture people accessing

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assessment through Right to Choose or private providers that do not report to MHSDS; and cannot yet reliably report how many people receive an ADHD diagnosis following assessment or what treatment they subsequently receive.[2,6]

This is therefore not simply an informatics problem. National Health Service (NHS) England has acknowledged that ADHD-related activity has been difficult to identify consistently because of limitations in granularity, coding and completeness across existing data-sets.[5] Similar limitations in pathway visibility matter clinically and operationally: if systems cannot reliably distinguish where people enter a pathway, whether referrals progress, where delays or disengagement occur, what assessment outcomes are reached or what support follows, clinicians and commissioners may be responding to a visible backlog without seeing the processes that generate it. The central problem is therefore not lack of data alone, but lack of sufficiently coherent and interpretable pathway intelligence.

Current data infrastructures are improving, but remain incomplete

NHS England is actively improving neurodevelopmental data quality and reporting, including through its ADHD data improvement programme.[5] However, current national data do not yet provide a coherent end-to-end view of autism and ADHD pathways. The latest autism waiting time statistics remain experimental statistics (official statistics in development) and describe progression primarily from referral for suspected autism to first care contact.[1] Autism activity delivered through CAMHS and adult mental health services is captured through MHSDS, but community paediatric autism assessments reported through CSDS cannot yet be identified consistently and are therefore excluded from the national autism waiting time statistics.[1]

ADHD reporting has similar limitations. Current national management information draws on several existing sources, including MHSDS, community paediatrics waiting list data and primary care registration data.[2,6] NHS England acknowledges that ADHD activity has been difficult to identify consistently because existing data lack sufficient granularity and completeness.[5] Current reporting cannot determine the total number waiting specifically for ADHD assessment, fully capture Right to Choose or private provider activity where providers do not report to MHSDS, reliably identify how many assessments result in an ADHD diagnosis or describe subsequent treatment.[7] The national improvement plan therefore aims for pathway data that are consistently defined, linkable and able to follow people from referral through to outcomes.[5]

The problem is therefore not simply the quantity of available data, but whether different data sources represent pathway stages sufficiently consistently to support valid interpretation. Dashboards and analytical tools may improve presentation, but they cannot compensate for incomplete coverage, inconsistent definitions or poorly visible transitions between referral, assessment, diagnosis, treatment and follow-up. Improving pathway intelligence requires clearer pathway logic and more coherent reporting before increasingly sophisticated analytics can reliably guide service change.

Data visibility extends beyond diagnostic status

A further blind spot concerns whether routine data can show how people enter, progress through and leave autism and ADHD pathways. Waiting list counts alone do not distinguish referral disposition, progression to assessment, disengagement or assessment outcome. Autism pathway guidance identifies different outcomes following referral and assessment, including progression, discharge and onward referral, and recognises diagnostic conversion as a potentially useful pathway measure.[3] For ADHD, current national reporting cannot yet reliably determine how many people receive a diagnosis following assessment or what treatment they subsequently receive.[7] Pathway visibility should therefore extend beyond waiting list size to include referral acceptance, redirection or decline, progression to assessment, assessment outcome and disengagement. For ADHD, clinically relevant treatment stages such as medication initiation, titration, monitoring and prescribing responsibility are also important.[4–6]

Diagnostic granularity is part of the same problem. A recorded ADHD diagnosis does not by itself describe symptom profile, functional impact, support need or treatment stage. DSM-5-TR includes current severity specifiers of mild, moderate and severe, whereas ICD-11 distinguishes ADHD clinical presentations without an equivalent mild/moderate/severe severity-specifier framework.[7,8] Neither classification provides a continuous severity scale as part of the diagnostic classification itself. Pathway intelligence should therefore avoid treating a diagnostic code as a complete proxy for functional impact or service need: people with the same diagnosis may have substantially different impairment, co-occurring conditions and treatment or support requirements.

Pathway position, diagnostic status and need are also distinct. A person whose referral is declined or redirected, someone awaiting assessment, someone who disengages before assessment and someone who completes assessment without receiving a diagnosis represent different pathway states.[3,6] If these are collapsed into aggregate referral, waiting list or diagnostic counts, important points of exclusion, disengagement or unmet need may remain hidden.

Diagnostic disclosure adds a further layer but should be interpreted according to age and context. Among autistic adults, disclosure decisions have been shown to involve potential benefits, including greater understanding and support, alongside concerns about stigma, misunderstanding and negative responses.[9] These findings should not be assumed to operate identically in children and young people. School and peer environments are particularly relevant in CYP: experimental research in a UK school found that disclosure of an autism diagnosis influenced some dimensions of peer stigma, although it did not uniformly reduce stigmatising attitudes.[10] The evidence cited here relates specifically to autism; equivalent mechanisms should not be assumed for ADHD without supporting evidence.

For autism and ADHD pathways, data recording is therefore not a neutral administrative exercise. It determines whether systems can distinguish demand from progression, referral acceptance from exclusion, waiting from disengagement and diagnosis from functional or support need.

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Better pathway intelligence requires these states to be visible separately rather than inferred from waiting list size or the presence of a diagnostic code alone.

Why this matters for equity and decision-making

These blind spots have direct equity implications. In a national cohort of more than 7 million pupils in England, recorded autism prevalence varied substantially by race/ethnicity and socioeconomic disadvantage, with the authors noting that such differences may reflect variation in detection and referral as well as underlying prevalence.[11] National evidence also points to disparities in access to neurodevelopmental assessment and support among girls, ethnic minority children and those from disadvantaged backgrounds.[12]

Importantly, inequity may arise before a person appears on a waiting list. Differences in identification, referral, referral acceptance, redirection or decline may shape who enters and progresses through a pathway. These stages should therefore be examined, where data quality permits, across key equity variables including age, sex/gender, ethnicity and socioeconomic disadvantage. Without pathway-level visibility, differences in recorded assessment or diagnosis cannot readily be distinguished from differences in access, referral behaviour or progression through services.[11,12]

Averages can therefore conceal important variation. A single waiting time measure may obscure whether particular groups enter pathways later, experience delay at specific stages, disengage before assessment or receive different levels of support while waiting. This is particularly relevant to Integrated Care Systems, whose core purposes include improving population health and tackling inequalities in outcomes, experience and access. Better pathway intelligence would allow commissioners and clinicians to identify where inequity arises and target service changes accordingly, rather than focusing only on the most visible backlog.

Weak pathway visibility also has practical consequences for primary care and specialist teams. Where referral routes, pathway position or support while waiting are unclear, people and families may return repeatedly to primary care or other services for information and support. Better end-to-end visibility would not remove workforce or capacity constraints, but it could make decisions about prioritisation, support and service redesign more transparent and accountable.

System mapping before dashboards

The next step should not be further dashboarding or predictive analytics in isolation; these tools are useful only if the pathway stages and data beneath them are sufficiently well defined. Structured system mapping should therefore establish three connected views: the intended pathway, describing how services expect people to progress; the experienced pathway, identifying delay, disengagement, re-entry and transitions experienced by people and families; and the data pathway, identifying where information is recorded, how it moves between organisations and where it becomes incomplete or cannot be linked.

Mapping should then inform a minimum viable data-set, rather than an aspirational list of variables. A first tier should prioritise information that can already be recorded through existing national data structures. Current MHSDS and CSDS technical guidance supports recording of referral and primary reason for referral, assessment activity, diagnosis, relevant care contacts and discharge or end of referral.[13,14] The relevant infrastructure differs by service: CSDS is particularly important where CYP ADHD assessment is delivered through community paediatrics, whereas adult ADHD activity is more commonly expected to flow through MHSDS.[5] The first priority should therefore be improving the completeness and consistency of these existing fields before requiring additional data collection.

A pragmatic core could include referral date and reason, assessment activity and date, assessment outcome, waiting intervals, diagnosis and discharge or end of referral, alongside core equity variables such as age, sex/gender and ethnicity. Referral disposition, including acceptance, redirection or decline, should also become visible because exclusion can occur before a person reaches a waiting list. For autism, NHS England already recommends consideration of conversion rates, defined as the proportion diagnosed following assessment; for ADHD, the analogous diagnosis rate is an identified national reporting priority, although incomplete recording has limited its reliable calculation.[3,5]

A second, enhanced tier should contain measures that require better linkage, more consistent recording or changes to reporting. For ADHD, this includes medication initiation, titration, monitoring and prescribing responsibility, including transitions to shared care.[4] CSDS can already record some medication review activity,[14] but an end-to-end account of prescribing may require linkage across specialist, primary care and independent or Right to Choose provision.[6] Similarly, broad labels such as ‘co-occurring needs’ should be avoided in favour of defined measures of recorded co-occurring neurodevelopmental, mental health or physical health conditions and identified support or reasonable adjustment needs.

Crucially, coherence does not require every provider to use a single information technology system. For CYP ADHD in particular, the more immediate priority is coherent reporting across systems through shared definitions of pathway stages, consistent coding and data fields, common clock points and linkage where feasible. NHS England’s ADHD data improvement plan similarly emphasises completeness, consistency, coherence and comparability across providers.[5] Where information cannot currently be linked or consistently recorded, this should itself be treated as a pathway finding and used to prioritise subsequent infrastructure improvement.

This staged approach is consistent with learning health system thinking, in which routinely generated data are converted into knowledge and used to support continuous improvement.[15] System mapping and minimum data-set alignment are therefore not ends in themselves: they provide the infrastructure needed to identify problems, test changes and determine whether pathway performance and equity improve.

What should change now

Reform of autism and ADHD pathways should move from better description to a staged cycle of mapping, measurement

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and service improvement. As a pragmatic 6-month pilot, Integrated Care Systems could use three sequential phases.

First, in months 1–2, map the pathway. A multidisciplinary group involving clinical services, primary care, commissioning, data / business intelligence (BI) teams, education / Special Educational Needs and Disabilities (SEND), where relevant, and people with lived experience should use the three-view framework described above to map the intended, experienced and data pathways. The output should identify major hand-offs, delays, referral redirection or decline, disengagement, Right to Choose interfaces and points where information is absent or cannot be linked. Mapping should be diagnosis- and age-specific where pathways genuinely differ.

Second, in months 3–4, test a minimum viable data-set. This should prioritise information that can already be captured through existing MHSDS and CSDS structures, including referral and reason, assessment activity and outcome, waiting intervals, diagnosis, discharge or end of referral and core equity variables.[13,14] Referral disposition and diagnostic conversion should be included where recording quality permits.[3,5,6] Additional measures should be introduced only where infrastructure can support them; for ADHD, these may include medication initiation, titration, monitoring and prescribing responsibility.[4] Coherent reporting should be pursued through shared definitions, coding and clock points across providers rather than requiring a single information technology system.[5]

Third, in months 5–6, use the data to test a specific service change. A pathway governance group should identify one or two priority problems, assign a named owner, agree a measurable change and review its effect at a defined time point. Examples might include clarifying referral criteria where referrals are repeatedly redirected, improving support or communication while people wait, reducing avoidable disengagement, strengthening information transfer from Right to Choose providers or improving ADHD shared care arrangements. The change should be retained, adapted or discontinued according to the resulting data and any unintended effects, including differences across priority equity groups. This iterative approach is consistent with learning–health system principles in which data are used to test and refine changes rather than simply report performance.[15]

Within 6 months the system should therefore have produced an agreed pathway map, tested a feasible core data-set and completed at least one measurable service improvement cycle. The aim is not to replace action on workforce or waiting times, but to make those actions more targeted, accountable and responsive to where pathway problems actually occur.

Towards more effective pathway reform

Autism and ADHD pathway reform cannot be guided by backlog counts alone. Systems need visibility of where people enter, progress through, disengage from and leave pathways, and how these patterns differ by diagnosis, age group and equity characteristics.

We propose a staged approach: map the intended, experienced and data pathways; establish a minimum viable core data-set supplemented by diagnosis- and age-specific measures; improve coherence across reporting systems; and use the resulting intelligence to test and refine service changes. This does not require a single data-set or information technology system, but it does require shared definitions and sufficiently consistent reporting to interpret pathway flow.

Better pathway visibility should complement, rather than replace, action on workforce, capacity and waiting times. Future research should prospectively test the feasibility of this approach in regard to whether it improves service delivery, equity and patient experience.

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Data availability

No primary data-sets were generated or analysed for this article. The article draws on publicly available reports, statistical publications and peer-reviewed literature.

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Author contributions

S.R. and C.T. conceived the article and developed the central argument. S.R. drafted the manuscript. G.C., B.A. and C.T. contributed service, policy and system perspectives and critically revised the manuscript. All authors approved the final version.

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Ethical standards

Ethical approval was not required because this is an opinion article based on publicly available sources and does not report original research involving human participants.

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