

Support for children and young people with special educational needs

November 2024

About us

The <u>NHS Confederation</u> is the membership organisation that brings together, supports, and speaks for the whole healthcare system in England, Wales, and Northern Ireland. The members we represent employ 1.5 million staff, care for more than 1 million patients a day and control £150 billion of public expenditure. We promote collaboration and partnership working as the key to improving population health, delivering high-quality care, and reducing health inequalities. As such, we will predominantly focus on the health workforce rather than social care in this submission.

Executive summary

Waiting lists for children and young people with special educational needs (SEN) in both education and NHS settings are too long, and this has lifelong impacts. Real-terms cuts to local authority budgets and increasing financial pressures on NHS services, combined with increasing levels of need for services have caused a perfect storm of waiting lists of up to four years in some parts of the country.

Despite the huge challenges, there are some pockets of good practice. These examples are characterised by being planned and delivered at "place" and "neighbourhood" levels, with strong involvement in the design of services from local communities and multiple agencies working together.

The additional funding announced at the Autumn Budget for SEN and alternative education provision has been welcomed, but much wider policy reforms are needed to ensure children and young people can access joined-up care and support in a timely way. These include better alignment between funding cycles across Whitehall, for funding cycles to be longer-term and for local public service leaders to have more autonomy over how to spend their funding to meet population need.

In addition, the use of NHS numbers as a unique identifier for children across different services would better ensure children and young people with SEN get joined-up care across agencies.

Performance of the system

- 1. Community service waiting lists for children and young people's (CYP) services now equal more than 270,000, with neurodevelopmental assessments occupying a significant share of these¹.
- 2. Additionally, waiting times for some children and young people waiting for mental health services, where CYP with SEN will also be seeking support, is still very long, with some waiting just over two years for first contact with services.²
- 3. Delays to care for younger patients who need support with SEN have lifelong impacts, including on educational attainment and subsequent employability as well as increased demand from other public services such as health, justice, or welfare.³
- 4. A 27 per cent real terms reduction in core spending powers for local authorities since 2010 has made it increasingly difficult for CYP SEN services to deliver well.⁴ This has driven increased demand for NHS services and anecdotally, has driven the increase in the numbers of children not attending school. In turn, this increases demand on NHS services for mental health and neurodiversity support as children and young people become less able to cope without support in schools, which many council areas have been forced to cut.
- 5. As of March 2023, 65 per cent of local authorities had cumulative deficits on the part of their budgets reserved for schools spending, with the primary reason being the cost of meeting their statutory duties to those with SEN.⁵
- 6. Some local authorities have signed deals with the Department for Education which sees them provided with additional funding for SEN provision if they carry out stipulated reforms intended to bring SEN spending.⁶ However, these reforms are a long-term plan and are controversial in some parts of the SEN sector.
- 7. The further £1 billion of funding for SEND and alternative education provision announced at the Autumn Budget is welcome, but local government has been clear that this will only help expand provision if it comes alongside fundamental reform of the SEND system, focussing on improving inclusion in mainstream settings and writing off councils' high needs deficits.⁷
- 8. In the meantime, the NHS continues to absorb the increased demand caused by less support available for children and young people at school. There has been a

¹ Children's Commissioner (2024) *Children's mental health services 2022-23* https://www.childrenscommissioner.gov.uk/resource/childrens-mental-health-services-2022-23/

NHS England (2024) Mental Health Services Monthly Statistics https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-services-monthly-statistics
 NHS Confederation (2024) The Future of Children's and Young People's Services

³ NHS Confederation (2024) *The Future of Children's and Young People's Services* https://www.nhsconfed.org/system/files/2024-10/Future-of-CYP-services.pdf

⁴ Local Government Association (2024) *Council Pressures Explained* https://www.local.gov.uk/about/campaigns/save-local-services-council-pressures-explained

⁵ Institute for Government (2024) SEND spending needs reform to stop local authorities going bust https://www.instituteforgovernment.org.uk/comment/send-spending-reform-local-authorities bust blid.

⁷ Local Government Association (2024) *LGA Statement on Autumn Budget 2024* https://www.local.gov.uk/about/news/lga-statement-budget-2024-0

- significant increase in CYP requesting an autism assessment an estimated 306 per cent rise.8
- 9. The National Institute for Health and Care Excellence (NICE) recommends that autism assessments should take place within three months of referral⁹, but with the increase in demand, this is rarely happening. Some members have told us CYP have had to wait over four years for an assessment in their local area. Anecdotally, members of the NHS Confederation's mental health network also tell us this is the length of wait for ADHD assessments in some parts of the country.
- 10. In the summer, 87 per cent of Integrated Care System leaders told the NHS Confederation they will not be able to meet their ambitions within their current budgets. Thirty-one out of England's 42 integrated health systems have a deficit plan for the year.¹⁰
- 11. In the context of these complex financial pressures on both the NHS and local authorities, Ofsted has identified a number of weaknesses with implementing SEN provision; a lack of joint commissioning, no or limited co-production, poor quality education, health and care plans (EHC plans) and lack of clarity about who is or should be held accountable for services and provision.¹¹

Overall picture on the support available and outcomes achieved for those with SEN

- 12. Despite long waiting lists, increased demand and huge financial pressures, there are pockets of good practice that are taking place through working innovatively using an asset-led approach at neighbourhood level.
- 13. In Wormley and Turnford in Hertfordshire, a community-led initiative focused on empowering residents to address local challenges such as social isolation, mental health, and youth engagement by transforming existing community spaces and partnering with local organisations is support CYP with SEN.
- 14. The Wormley Community Centre serves as a hub for community activities, with one focus being reducing anti-social behaviour among children and young people, by providing positive, engaging alternatives. Programmes like the DJ and MC Academy are designed to offer young people creative outlets and skill-building opportunities, providing social activities and reducing the likelihood of anti-social behaviour. New activities such as roller-skating lessons, fishing workshops, and self-defence classes are designed to be inclusive, providing opportunities for children, including those with SEN.¹²
- 15. The hub has been possible through collaboration with local charities, councils, and businesses is at the heart of the initiative. To date they have worked with Broxbourne and Hertfordshire councils, more than 50 local charities, Citizens Advice, and local churches, taking a grassroots approach being led by residents who serve as trustees

⁸ Centre for Young Lives (2024), *An evidence-based plan for addressing the autism assessment and support crisis* https://www.centreforyounglives.org.uk/news-centre/new-analysis-reveals-autism-assessment-and-support-crisis-with-tens-of-thousands-of-children-waiting-months-and-years-for-help-after-demand-rockets-by-over-300-since-covid

⁹ NICE (2021), Autism spectrum disorder in under 19s: support and management https://www.nice.org.uk/guidance/cg170/chapter/recommendations

¹⁰ NHS Confederation (2024), *State of Integrated Care Systems* 2023-4 https://www.nhsconfed.org/publications/state-integrated-care-systems-202324

Ofsted (2021) SEND: old issues, new issues, next steps https://www.gov.uk/government/publications/send-old-issues-new-issues-new-issues-next-steps
 NHS Confederation (2024) Case Study: Wormley and Turnford / Broxbourne Big Local

¹⁴ NHS Confederation (2024) Case Study: Wormley and Turnford / Broxbourne Big Local https://www.nhsconfed.org/case-studies/wormley-and-turnford-broxbourne-big-local

and staff. The helps ensure the project uses feedback gathered through events and informal interactions to continually adapt its strategies and be responsive to local needs.

- 16. However, the initiative faces challenges in securing consistent funding, with the current economic climate making it difficult to sustain and expand its projects. Delays and competition for funding can impede service delivery and planning. The initiative relies heavily on external funding, such as grants from the National Lottery and local councils. This dependency creates vulnerability to shifts in funding priorities and requires continuous efforts to secure diverse funding streams.
- 17. In parallel, children's community services in Hertfordshire have half waiting times for access to services for neurodiversity from 120 to 60 weeks (albeit this is still far too long.)¹³
- 18. In Portsmouth, the local authority holds regular meetings, gathers feedback, creates surveys and listens to feedback from children, young people, parents and carers on services, with a particular focus on improving accessibility. In response to this, it has co-produced the new website and involved parent carers and young people in all of the decision making to make sure its new SEND Local Offer website works for everyone. Every three months a Local Offer information and advice co-production group meets to discuss developments: the transcripts of these discussions are shared with senior management which makes decisions about services and support and uses it to understand what needs to be in place to support children and young people with SEND across Portsmouth.¹⁴
- 19. What is key in both these examples is the focus on local communities and coproduction, and particularly in the case of the Wormley Community Centre, taking an assets-based approach.

Government action to create a sustainable SEN system and restore confidence

- 20. The funding announced for diagnostic tools and other capital funding at the Autumn Budget was welcomed by health and care leaders. Our members hope it will be allocated with minimal criteria so that local health leaders can allocate it to best meet the health needs of the communities they serve.
- 21. For our mental health and community sector members, some will wish to spend it commissioning digital services for mental health support, including for autism and ADHD provision. These have the potential to both reduce the burden of long waits on children and young people and simultaneously use NHS resources more efficiently. NICE guidance should be updated accordingly to encourage uptake where clinically appropriate.
- 22. The government should encourage and where necessary, provide resource for, improving digital access and online resources to reduce the impacts of long waits on patients and their families alike; empowering parents to support their child and navigate the options available to them. Information about how symptoms present in

¹³ NHS Confederation (2024) NHS Voices: Community Services Week https://www.nhsconfed.org/articles/elliot-howard-jones-we-ped-empower-these-services-across-country

we-need-empower-these-services-across-country

14 Portsmouth Local Offer (2024), *About Us* https://portsmouthlocaloffer.org/information/neurodiversity/

- children and young people should be made more easily accessible to parents and carers in order to support and empower them, as well as reducing pressure.
- 23. In addition to these actions, there is important work for government to do to deliver their stated shift towards a Neighbourhood Health Service. This will be key for ensuring CYP SEN services can meet the level of need across the population.
- 24. Public bodies with responsibility for the health and development of under-18s should examine the benefits of working within Multi-Disciplinary Teams (MDTs) at place and neighbourhood levels to support children and young people. This means government devolving decision-making about the funding, design and delivery of local services using the principle of subsidiarity.
- 25. There needs to be better alignment of funding cycles across Whitehall, but particularly between the Department for Health and Social Care, the Department for Education and the Ministry of Housing, Communities and Local Government. This will ensure services can be better integrated and where appropriate, budgets pooled to deliver joined-up services.
- 26. These funding cycles need to be longer-term, rather than short-term pots allocated for specific projects or services. This will allow local health and care leaders to design and deliver services in a way that best meets local population need for services.
- 27. NHS numbers and pupil identifiers should be consolidated in order to trace children and young people's needs between NHS services, education, and other bodies such as local government to ensure children and young people with SEN get joined-up care across agencies.
- 28. More widely, costs to the NHS need to be calculated longitudinally, with investment in children and young people having some of the greatest returns of all interventions.

 The Chancellor's changes to fiscal rules announced at the Autumn Budget to see NHS investment used as an explicit tool of economic development.

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¹⁵ NHS Confederation (2004) Pathways to Prevention https://www.nhsconfed.org/publications/paving-new-pathway-prevention

¹⁶ NHS Confederation (2023) Creating Better Health Value https://www.nhsconfed.org/publications/creating-better-health-value-economic-impact-care-setting