

Children and young people's health

This is the 2023/24 edition of State of Care

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Secondary care

We know that getting care the right care, at the right time in the right place is important for all patients. But not getting the care they need when they need it can be particularly damaging for children.

The <u>Royal College of Paediatricians</u> has previously flagged concerns about the numbers of children waiting for elective care treatment. In May 2023, it highlighted that there were over 400,000 children on the waiting list for consultant-led paediatric services. While this has subsequently reduced to 363,000 by June 2024, over 140,000 of these had already waited over 18 weeks.

Delays to treatment for children can have significant consequences. Many treatments and interventions must be administered within specific age or developmental stages. Treatments and interventions may be less effective if not administered within these stages, and the opportunity to intervene can be missed completely if the wait for diagnosis is too long.

Additional impacts include the loss of schooling, financial impact for families with carers missing work, and disruption to family life. These effects are often greatest for the most vulnerable children and families. For example, a child waiting to be seen in clinic for specialist asthma treatment may be missing school due to their symptoms, as well as being at increased risk of an episode of severe or life-threating exacerbation of asthma requiring an inpatient admission.

Between 1 April 2022 and 31 March 2023, 3,743 children aged 0 to 17 died in England. The causes of child mortality are numerous and complex. However, we are concerned that this represents an increase of 8% on the previous year and the highest number of deaths recorded since the National Child Mortality Database was launched in 2019.

We also have concerns that in an emergency, children and young people are not always able to access services promptly. An analysis of a sample of our inspection reports shows specific issues in urgent and emergency care services, including low numbers of qualified staff – specifically children's nurses – and gaps in staff training in subjects such as safeguarding and sepsis recognition. These issues meant that in some services, there was a risk that a deteriorating child might not be identified quickly, and patients at risk of sepsis not being assessed and treated promptly.

We found that crowded emergency departments meant waiting areas did not always assure the safety of children and young people. In one case, staff could not ensure appropriate visual supervision or carry out risk assessments and mitigate risks in waiting areas.

Anecdotal evidence suggests that parents and carers are well-placed to recognise when their child is very unwell. Therefore, actively involving parents in their child's care decisions and addressing their concerns promptly is critical to safety.

In May 2024, we commissioned a survey of parents with children aged 0 to 18 years who had taken their child to see a healthcare professional in the last year. Of the 1,000 respondents, 44% (439) stated they had raised a concern about the health of their child or children to a healthcare provider in the last year. Of these, 78% felt that the health provider took their concern seriously. However, in 22% of the cases they did not feel their concern was taken seriously. Where respondents had a negative experience, they described their experiences of staff with words such as 'dismissive', 'judgemental', 'not friendly', or 'not compassionate'.

Where people felt their concerns were not taken seriously (95 respondents), 86% felt there was a negative consequence, including:

- losing trust in the healthcare provider (49%)
- feeling like their child did not get the help they needed (41%)
- reporting their child's health deteriorated as a result (31%).

To support patients and families to get the care they need, in April 2024 NHS England introduced a pilot of 'Martha's Rule' in 143 hospitals across England. Martha's Rule will ensure that where patients are admitted to a hospital in England, information will be gathered daily from patients, families and carers. Martha's Rule also empowers patients, people who use services and their families and carers to seek a rapid critical care review if they feel their concerns are not being addressed by their current clinical team.

Martha's Rule reinforces the fundamental principles of listening to people who use health and care services and their families – and acting on what they say. It supports care that is person-centred, responsive, and aligned with high standards of professional practice.

We welcome the way that Martha's Rule emphasises effective teamwork, mutual respect, and open communication. The emphasis on professionals working together encourages active listening, promotes person-centred care and supports a culture of learning and improvement.

The introduction of Martha's Rule follows the rollout in November 2023 of the national paediatric early warning system (PEWS). The tool, developed in collaboration between NHS England and the Royal College of Paediatrics and Child Health and the Royal College of Nursing, attempts to standardise the recognition of, and response to, unwell children. It supports doctors and nurses treating children to quickly identify deterioration, escalate care, and act on parental concerns.

Children and young people's mental health care

In 2023, 1 in 5 children and young people between the ages of 8 and 25 were estimated to have a mental health disorder. Not getting the help they need when they need it can have a huge impact on children and young people.

Long waiting times could lead to children and young people feeling unsupported and as though they were not enough of a high risk to get help. People also spoke about how long waiting times could lead to a lack of trust in mental health services for children and young people.

One young person described the consequences of what they felt to be inadequate support from community services, leading to long-term hospitalisation:

"I didn't know what to do because I didn't have any GCSEs and I thought no one's gonna want to give me a job and I'm not gonna be able to go to college... I wasn't a

normal person of my age because I was in hospital and I missed out on all the things."

We also heard about the positive impact of getting the right support early enough:

"I do still think back on my time at CAMHS and I was like, if I didn't [get that support], I would be in such a different place today... I got very lucky."

Alex's story

Alex first started struggling with food at the end of 2020. Her dieting became gradually more extreme and then escalated in the summer of 2021 when she was rapidly losing weight.

Alex visited the GP in October 2021 who made a referral to children and young people's mental health services. She describes her visit to the GP as quite a negative experience:

"She (the GP) kept saying 'ohh Alex thinks she has this' and 'Alex feels she is bisexual' and I just immediately felt like [this service] was not gonna be very helpful to me because they just don't actually listen and they don't actually trust me because in their eyes, I'm a silly teenage girl instead of, like, an actual person who's going through actual things."

Anticipating a long wait for the service, Alex sought support from a private eating disorder therapist, which she found very helpful. However, Alex and her family still wanted to access family-based therapy and support from a nutritionist through children and young people's mental health services. Alex waited 7 months for initial contact from the service. Nutritionist support was put in place quickly after that, but the wait for therapy was another 6 months. Alex did not feel she was kept well informed while she was waiting for care and regularly had to call for updates, which were always very vague.

In November 2022, Alex started therapy with an eating disorder specialist from the children and young people's mental health service. However, she didn't develop a good relationship with the therapist and felt they patronised and misunderstood her. She found these sessions so frustrating that she would regress with her eating because of them, so she decided to discontinue the therapy.

"This was really upsetting because we've been on a wait list for a year to receive therapy and now that therapy was doing me more harm than good."

After 8 months of waiting, Alex was given an appointment with a psychiatrist to support with the underlying depression. By this point, Alex wasn't struggling with depression anymore, so it was decided no further support was required. However, the psychiatrist suspected that Alex had ADHD (attention deficit hyperactivity disorder). Assessments were then carried out quickly to get a diagnosis, which allowed Alex extra time and rest breaks when she sat her A-Level exams in the summer of 2023 – something that she is very grateful for.

Alex was still receiving support from her private therapist throughout this time, who she found she was making great progress with. When she reached her 18th birthday and was discharged from children and young people's mental health services, she decided she didn't want to be referred to adult mental health services.

(Interview with a member of the public)

Community health care

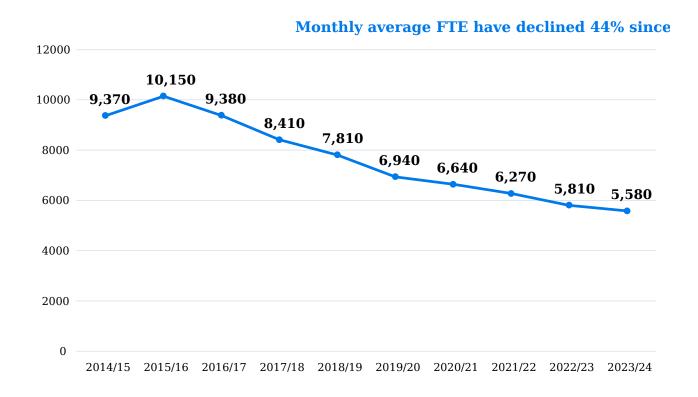
Overall NHS nursing numbers have increased by 21% from 2015/16 through 2023/24, including a 10% increase in community health nursing.

However, for several key roles in the community health care sector, there have been reductions in numbers. The largest reduction is in monthly average numbers of qualified health visitors, which we examine in more depth.

Health visitors are registered nurses or midwives who have undertaken additional training in community public health nursing to provide individual support and advice for families with a new baby, from late in the antenatal period up to 5 years of age.

The number of qualified health visitors has seen a sustained decline. Between 2015/16 and 2023/24, the monthly average number of FTE health visitors has decreased by 45% – the equivalent of over 4,500 FTEs (figure 19). (Note, these figures reflect the data published by NHS England, which excludes non-NHS providers such as community interest companies.)

Figure 19: Monthly average of health visitor full-time equivalents in England, April 2014 to March 2024



Source: NHS Workforce Statistics, May 2024, NHS England

This decline could be partly explained through a greater percentage of health visitors giving 'retirement' as a reason to leave their jobs, compared with nursing staff overall. Health visitors are a comparatively older workforce – based on a snapshot of staff in post on 31 March 2024, 75% of qualified health visitors were over 40 years old, and 28% were over 55. Less than 5% were under 30. By contrast, in the overall nursing workforce, 50% were aged over 40, 15% over 55 and 16% were under 30 years.

Despite the sharp reduction in numbers, responses from health visitors to the 2023 NHS Staff Survey were better than comparable staff across many key areas. However, compared with registered nursing overall, the one major theme associated with lower scores from health visitors was for 'work pressure' – potentially pointing to the additional workload placed on this decreasing resource. Health visitors also reported they were significantly more likely to work unpaid hours and scored lower in reporting a manageable level of demands on their time.

The <u>analysis</u> by the <u>Institute of Health Visiting (IHV) of its 2023 survey</u> identifies that infants under 1 year have the highest proportional representation in emergency departments compared with other age groups. Attendance rates for infants aged 0 to 4 years increased by 42% between 2012/13 and 2022/23, from 1.8 million to 2.6 million. The IHV suggests that a large proportion of these attendances could have been avoided if better access to health visiting services had been available.

The IHV goes on to give an example that, in North West London, 59% of babies who attended an emergency department in 2022 did not need treatment and were sent home after reassurance, costing an estimated £1.8 million a year in this one area of London alone. While acknowledging that the emergency department is the right place for very sick babies and young children, the IHV says improving access to high-quality care in the community could help to reduce attendance in babies and young children, and reduce undue worrying for parents.

In an article on improving childhood vaccine uptake, the IHV points out that vaccination is one of the most effective public health interventions available, preventing illness and disability, and saving lives, and that health visitors have a role in raising awareness of its importance. There has been a 43% reduction in the uptake of the measles, mumps, and rubella vaccine, as well as other vaccines in the last decade. While other factors will have influenced this, the reduction correlates with the decline in the number of health visitors over a similar period.

Another result of declining numbers of health visitors is having insufficient time to build and maintain longer-term relationships with families, with a latest IHV survey finding that less than half (48%) feel able to do this.

The ambition of the NHS Long Term Workforce Plan is to expand the number of training places for health visitors by 74% to address preventable child illness and take the pressure off stretched emergency departments. However, since the ambition is to reach this by 2031/32 and, considering the length of time it takes to train (2 years for a qualified nurse or midwife), this means it may be some time before an improved health visitor resource could have the desired effect. While this is the first focused effort on increasing health visitor numbers since 2015, it may not address the reductions mentioned above, as there is no minimum standard for provision.

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