

Written evidence submitted by The Challenging Behaviour Foundation (DTY0064)

About The Challenging Behaviour Foundation:

The Challenging Behaviour Foundation is a UK-based charity which supports children, young people and adults with a severe learning disability and challenging behaviour and their families. We aim to make a real difference to the lives of children, young people, and adults with severe learning disabilities and those who care for and support them. Families are central to everything we do with carers represented at every level of the organisation across projects, trustees, staff, and volunteers.

Access to regular oral health checks and reasonable adjustments for treatment is particularly important for people with severe learning disabilities and autistic people. Many are non-verbal or have difficulties communicating, which mean symptoms of pain and discomfort are likely to go unnoticed and untreated for longer and may result in an increase in challenging behaviour. The Challenging Behaviour Foundation has gathered information about reasonable adjustments that can support patients with additional needs. <https://www.challengingbehaviour.org.uk/information-and-guidance/health/dental-appointments/>

For more information about The Challenging Behaviour Foundation go to our website:

<https://www.challengingbehaviour.org.uk/>

- 1. What steps should the Government and NHS England take to improve access to NHS dental services?**
 - a. What role should ICSs play in improving dental services in their local area?**

NHS England can improve access to dental services by publishing the *Clinical Standard of Oral Healthcare for Autistic Children & Young People and/or those with a Learning Disability in Special Education Settings*. The standard was completed in early 2022, and to the best of our knowledge there is no publication date planned.

The clinical standard provides important guidance on oral health checks and accessible treatment for people with severe learning disabilities and autistic people. It details how to make reasonable adjustments to accommodate additional needs such as remote checks in familiar environments. Reasonable adjustments for people with disabilities are a legal entitlement under the Equality Act 2010. If published, the standard would go a long way to informing professional practice and improving accessibility.

There are serious implications as a result of the delay in publishing the clinical standard. At the Challenging Behaviour Foundation we continue to receive contact from families via our charity helpline who are unable to get adequate dental care for their children, leaving them in pain and distress. We have also heard from a School Nurse Manager who reported that the current “dental contract arrangements are a disaster” and that they are seeing “a higher incidence of behaviours potentially triggered by dental pain but can’t get access to services to assess and support”. The new clinical guidelines contain important information to address these issues and there is significant benefit in implementing these without further delay.

The publication of these reports should be considered a priority because they support goal 3.32 in the NHS Long Term Plan to “work with partners to bring hearing, sight and dental checks to children and young people with a learning disability, autism or both in special residential schools.” The plan

states “We will ensure that reasonable adjustments are made so that wider NHS services can support, listen to, and help improve the health and wellbeing of people with learning disabilities and autism, and their families. Over the next five years, we will invest to ensure that children with learning disabilities have their needs met by eyesight, hearing and dental services, are included in reviews as part of general screening services and are supported by easily accessible, ongoing care” (page 41). Further delay in publication will mean this goal is not met.

As well as the NHS England Long Term Plan, the publication of the clinical standard is in line with the NHS CORE20PLUS5 approach to reduced health inequalities. NHS England has identified young people with severe learning disabilities as a target population to reduce healthcare inequalities ('PLUS') and oral health as one of the five key clinical areas of focus ('5')

(<https://www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/core20plus5/core20plus5-cyp/>).

As stated by Sara Hurley (Chief Dental Officer England) in the foreword of the clinical standard, “This strong focus on prevention is not only ethically the right thing to do, it is also a financially astute intervention to deliver return on investment”. Significant time and NHSE & I funding have been allocated to this important work, producing new standards and resources that can deliver good outcomes for children, young people and families and others that support them, as well as being cost effective for the NHS by preventing unnecessary tooth decay.

2. How should inequalities in accessing NHS dental services be addressed?

During consultations with families of individuals with profound and multiple learning disabilities, The Challenging Behaviour Foundation has found a variety of barriers to accessing dental services. Our findings in surveys and focus groups revealed that a major barrier to equitable access is discrimination and lack of reasonable adjustments. Many patients are not given reasonable adjustments despite their legal entitlement under the Equality Act 2010. This reality is demonstrated in some of the comments from families:

- *“There is clear discrimination. We waited weeks and months for dental referrals then the hospital said they would not do dental treatment. That was it. There was no learning disability nurse.”*
- *“If you want to know what I think about something, you need to give me information about it” “If you want me to have a successful experience, you will need to find out about me before I see you...”*
- *“A familiar setting would really help get the best out of appointments. My son gets anxious in unfamiliar setting particularly anything that feels like a hospital. He becomes upset or completely shuts down so it is impossible to assess him accurately.”*

Families shared with us reasonable adjustments that could help their child access dental care. The needs of each child are specific and require close collaboration with family/carers, but examples include clear communication, location-specific preparation, familiarization, and desensitization.

The NHS Health Education England e-Learning for Healthcare platform offers a programme of resources called ‘Mini Mouthcare Matters’, which are designed to assist the dental care treatment of young people with severe learning disabilities and autistic people in Specialist Education Settings (Health Education England, e-Learning for Healthcare, e-lfh.org.uk). They detail how remote oral health checks might be performed in schools or a familiar environment to make them more

accessible. If the government and the NHS invested in these practices, it would have a big impact on increasing the accessibility of dental care for this group of young people. Further evidence and support for the use of remote oral health checks is given in the *Clinical Standard of Oral Healthcare for Autistic Children & Young People and/or those with a Learning Disability in Special Education Settings*, which if published would lend support to tackling inequity of access.

Another barrier to access is the lack of understanding around communication, consent and learning disabilities. Families identified poor understanding around mental capacity, best interests and consent, even among specialist healthcare professionals. Further, they reported that professionals fail to listen to concerns, observations or challenges identified by families and carers. Diagnostic overshadowing is a well-documented issue for people with severe learning disabilities and was experienced by the families we consulted. It occurs when symptoms of health are wrongly attributed as a part of an individual's learning disability and dismissed, rather than being properly investigated and treated. Some comments from families include:

- *"The attitudes we faced were rude and dismissive, even at the special care dentist."*
- *"My daughter goes for yearly sight checks. We noticed she had "wobbly eyes" so we asked for her to be checked and we were told she could see the pictures and there is nothing wrong. But we think there is something wrong and no one will believe us. We are not listened to."*

Specialist expertise and training in severe learning disabilities is needed to address these issues, including into communication and complex needs. There was also a specific point made that pica behaviour can be dangerous and dentists need to understand the implications for dental care and prevention.

Another theme identified in our consultations with family members was a failure to consider the least restrictive options possible. There were examples of restraint given where it was not clear that healthcare professionals had done all they could in advance to consider alternatives, minimize anxiety and to use the least restrictive method possible. For those age 16 years and over there is a legal duty under the Mental Capacity Act 2005 to consider the least restrictive option: "Before the act is done, or the decision made, regard must be had to whether its purpose can be as effectively achieved in a way less restrictive of the person's rights and freedoms."

Another issue identified by families was poor support around pathways including the transition from child to adult services at the age of 18 years old. They reported previous support dropping away, and difficulties accessing checks as an adult. Families talked about the lack of clear information and having to find their own pathways through services, often based on what other parents told them. Comments from families included that:

- *"My daughter is nearly six and we have not yet had a good experience. I had to take her to the dentist due to tooth grinding. They had a quick look and said all was fine. Her special school didn't do anything. She can't tell us if something is wrong. We have to find everything out for ourselves, mostly through other parents. There is no pathway or clarity about how or where to get any support."*
- *"There was a massive gap between child and adult services (age 16/17) where my son needed fillings, but no-one would treat him for a year as neither service would accept him."*

The families we engaged with identified changes and recommendations that would make a difference. Responses included:

- Information for families, including guidance on what a healthy mouth and good cleaning look like, an understanding of legal rights, clear standards and examples of good practice so families know what to expect.
- Clear pathways for support, included in Education Health and Care Plans, with attention to what is available locally and the transition from child to adult healthcare.
- An automatic requirement to contact anyone with a learning disability flag on their record regarding reasonable adjustments required ahead of appointments, and remote checks available at home, school or familiar environments.
- Frontline staff trained to understand how to communicate with and provide healthcare to people with severe or profound and multiple learning disabilities.

Seeking the views of young people who do not communicate using speech is challenging, but direct engagement is necessary to hear the voices of families and people with severe learning disabilities to ensure policy and best practice reflect lived experience and provide robust and practical guidance. The findings of The Challenging Behaviour Foundation here go some way in doing this, but further direct engagement and co-production is necessary to fully address dental care inequalities.

3. Does the NHS dental contract need further reform?

When the Challenging Behaviour Foundation consulted with carers of individuals with severe learning disabilities, a school nurse manager reported that there is difficulties in getting this group of children and young people access to the specialist expertise they require. They stated that:

- *“new dental contract arrangements are a disaster. We can no longer refer children to our specialist community dental team. They can only be referred by another dentist but as none are registered with an NHS dentist they have to cross this hurdle first. Currently NHS dentists are like gold dust.”*

4. What incentives should be offered by the NHS to recruit and retain dental professionals, and what is the role of training in this context?

N/A

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