

## Written evidence submitted by The National Network of Parent Carer Forums (DTY0092)

The National Network of Parent Carer Forums (NNPCF) is the independent, national voice of parent carer forums. We are run by parent carers with lived experience. The NNPCF is a representative organisation, consisting of up to 152 local parent carer forums at any time across England. Parent Carer Forums are pan disability. This means each parent carer forum includes parent carers from a range of backgrounds with a wide range of experiences in Health, Education and Social Care as their children have a wide range of conditions. We currently have approaching 118,000 members.

**Our vision** is for the best possible opportunities and futures for all children and young people with SEND and their families.

**Our mission** is to deliver better outcomes for families living with special educational needs and disabilities (SEND). We aim to create a culture of participation and co-production across the education, health, social care, and the voluntary sectors. This means that we are involved in all aspects of designing, commissioning, delivering, and reviewing services as an equal partner. We empower our members to ensure that their voices are heard at a local, regional, and national level inspire our partners by sharing good practice and knowledge.

This **submission** focuses mainly on the lived experiences of parents of children and young people with SEND and their experiences of NHS dentistry.

As a **membership organisation**, the NNPCF has based this evidence on reaching out to our networks of Parent Carer Forums. We asked our membership to feedback to us on the following areas:

- Inequalities children and young people with SEND face when accessing NHS dentistry
- How these inequalities can be addressed
- Ideas for improving access to NHS dentistry services for children and young people with SEND

### [Inequalities experienced by children and young people with special educational needs and disabilities](#)

#### [Attendance at typical community clinics](#)

Parent carers report difficulty in accessing community dentistry services for their children and young people with SEND. They report a lack of reasonable adjustments which would enable their child to access the clinics. Waiting rooms in clinics can be distressing for children and young people with sensory needs, and the distress caused by waiting for the appointment can create a barrier to accessing the dentistry services.

Dentists do not always have the information they need on a particular patient to be able to understand the barriers the child or young person with SEND may face, nor the training to ensure they can address those barriers. This creates a further potential barrier to accessing appointments as parent carers have to explain the needs of the child to the dentist.

Parent carers also report the challenges of attending dentistry appointments on top of a large number of other medical appointments for their child. There are some reports of dentist not understanding the many issues parent carers face, which is creating further barriers to attendance.

It is not uncommon for community dentists to refer a child with SEND to a specialist dentist if they require treatment. This creates further delay in treatment as the child sits on the waiting list for a specialist service.

### Attendance at specialist clinics

Children with SEND who are not able to access the same density in the community as others, are often referred to a specialist dentist. The NNPCF is aware that not all parent carers or medical services know how to get referred to a specialist dentist, nor that specialist dentists exist. Accessing these services can be fraught with difficulty, and often requires a consultant referral. Once the referral has been written, parent carers report finding it difficult to access information about the referral: whether it has been accepted, and how long the waiting lists are.

Parent carers have also experienced difficulties in getting appointments with the specialist dentists when they are required. One parent carer forum reports adult specialist dentistry services have resumed services as normal following the pandemic, however children's specialist dentistry services are still very disrupted.

### How these inequalities can be addressed

#### Improving training for community dentists

Dentists need to be able to access training on not only how to deliver dentistry to children and young people with SEND, but also how to make the dentist surgery more welcoming for these children. They need to understand the challenges children and young people with SEND face so they can reduce these inequalities in the future.

Dentists could also do with training on techniques to familiarise themselves with particular patients and how to run desensitisation sessions for those children and young people that need them. There also needs to be an understanding that there may need to be several desensitisation sessions before a child or young person with SEND is ready to have dental treatment.

#### Improving information and access to specialist dentist services

Children and young people with SEND should not face additional waiting times to access the dentistry services they require due to their disability. Information about specialist dentist services should be known, and parents able to access these services without a fight.

When a child is identified as needing transferring from a community clinic to a specialist clinic for treatment, this treatment should be provided on the same timescale as if they were able to receive the treatment at the community clinic.

### Ideas for improving access to NHS dentistry services for children and young people with special educational needs and disabilities

#### Home visits

For some parents of children and young people with SEND the barriers of attending a dentistry clinic may prevent access to dentistry services. For this group of children and young people home visits from dentistry services may help to reduce these barriers.

#### Improved planning

From next April, Integrated Care Boards need to ensure there is enough dentistry provision for children and young people with SEND both within community and specialist clinics.

Nationally, ensuring the dentistry needs of children and young people with SEND can be met within the current dentistry system is of vital importance.

#### Improved partnership and collaboration

The NNPCF would like to see local parent carer forums involved in all aspects of designing, commissioning, delivering and reviewing dentistry services for children and young people with SEND.

This will help to improve access to dentistry by ensuring lived experience is part of the planning and delivery of services.

Local parent carer forums can share experience of dentistry on a local level. Dentistry services, both in the community and specialist, should have an obligation to engage with their local parent carer forum to discuss how the dentistry needs of children and young people with SEND. Some parent carer forums may be able to share experiences of sensory barriers preventing access to dentistry, and how these barriers can be reduced, which may improve access to dentistry services in the community.

The NNPCF is keen to ensure children and young people with SEND do not face further barriers to accessing dentistry services because of their special educational needs and disabilities. The NNPCF has vast lived experience amongst its membership and would like to see a culture of participation and co-production with parent carers (which is already applicable in education and health) extended to dentistry on a national level to help reduce access barriers to dentistry. The NNPCF would be willing to explore in further depth barriers to accessing dentistry for children and young people with SEND, as well as work with the NHS to ensure the dentistry needs of these children and young people are met.

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