healthwatch
Oxfordshire

Your voice on health and care services

Children's oral health

What we heard from:

- Parents and carers in Banbury Neithrop and Ruscote
- Parents and carers of children with special educational needs and disabilities

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Summary

Oral health in children under 10 has been identified as a priority area under the **NHS Core20Plus5** programme aimed at tackling health inequalities. Having good oral health - healthy teeth and gums – is an important part of being healthy and well. Children who live in the most deprived areas are more likely to have problems with their oral health. Children with special educational needs and disabilities (SEND) are also more likely to face additional challenges looking after their oral health.

In September 2023, three local Healthwatch (Healthwatch Bucks, Healthwatch Oxfordshire and Healthwatch Reading) together received NHS Core 20 Plus (Children and Young People) funding via Buckinghamshire, Oxfordshire and West Berkshire Integrated Care Board (BOB ICB). We jointly took children's oral health as a priority. This enabled each Healthwatch to build a shared approach, as well as develop local place-based Community Connector models, focused on our most deprived areas.

A separate **joint overview** report highlighting common themes and recommendations from across the three Healthwatch groups, using the

Core 20 Plus approach, will be presented to the BOB ICB Prevention and Population Health Committee in July 2024.

This report outlines what Healthwatch Oxfordshire found at 'place' level, and is for attention of system partners in Oxfordshire.

From November 2023 to March 2024, Healthwatch Oxfordshire focused on hearing about experience of both barriers and support to oral health in children. We heard from a total of **96 people** via the following:

- ✓ Work under the **Core20Plus5** Scheme, to recruit five **Community Connectors** in Banbury Neithrop and Ruscote. These local Connectors built on their community links to reach 45 parents and carers (part-funded by NHS Core 20 Plus via BOB ICB).

In addition, we took the opportunity to build on this focus by widening our reach alongside as follows, as part of our regular work in Oxfordshire:

- ✓ Hearing from parents and carers of children in Oxfordshire with SEND across the country through an online survey and via outreach. We heard from 38 people.
- ✓ 9 **in-depth interviews** with caregivers of children with SEND.
- ✓ Wider **outreach in the community** aimed at hearing from families seeking asylum and in temporary hotel accommodation in Banbury.

What did we hear?

We heard that caregivers try hard to make sure that their children have good oral health.

Caregivers told us the **things that support** them to look after their children's oral health include:

- Having a good routine, especially for children with SEND.
- Finding the right toothbrush and toothpaste for their child, especially if their child has sensory needs.
- Supervising brushing or brushing teeth together as a family.
- Restricting sugary food and drink.

- Using resources like timers, apps, sticker charts, videos, books, songs or communication aids to explain why it is important to brush teeth and make it fun.
- Good advice and treatment from dentists, schools and other services.
- Support with healthy eating from schools and other childcare settings.
- Finding support from health professionals with an understanding of SEND.

They told us that things that **make it harder** to look after their children's oral health include:

- Difficulty finding an NHS dentist or waiting a long time for an appointment.
- Some special educational needs and disabilities - especially sensory needs and demand avoidance - make it hard to support children to keep their teeth clean or visit a dentist.
- The financial cost e.g. getting specialist toothbrushes and toothpaste, and access to healthy food.
- A lack of understanding or appropriate advice from dentists.
- Existing dental problems impacting oral health.
- A lack of and tailored information knowledge about good oral hygiene.
- Managing children's sugar intake in the wider food environment.
- Other factors including not having enough time or energy, the impact of difficult life circumstances, and wider caring responsibilities.

We heard in particular that there was **limited information tailored to the needs of oral health and SEND**. We heard that oral health professionals, and other professionals supporting children and families (like health visitors and social workers), are an important source of information and support. Caregivers of children with SEND also rely on advice from friends, family and others with lived experience, and seek advice via social media. People told us that advice needs to be given early and to be tailored to SEND where appropriate, and that they value when children are engaged with information to help them understand the importance of good oral health.

We heard about experiences of accessing and visiting dentists with a child and of tooth extractions. We heard that experiences were positive when dentists or other oral health professionals were able to make adjustments to accommodate the child's needs. For children with SEND, this happened most often at a specialist community dentist, but also at NHS dentists where staff had time, patience, awareness of SEND and listened to what the caregiver told them about their child's needs.

Caregivers suggested improvements to oral health services and promotion in Oxfordshire, including improving access to NHS dentists, clearer and more accessible referral pathways to specialist community dentists, training and support for oral health professionals, reasonable adjustments for children with SEND and promoting oral health awareness for caregivers.

Recommendations

In April 2024, Healthwatch Oxfordshire hosted an event in Banbury, where Core 20 Plus Community Connectors shared what they had learned from their conversations with the public and presented their findings to representatives from the health system. At this event we explored next steps with participants including with BOB ICB commissioners, Oxfordshire County Council Public Health, Thames Valley Community Dental Services - Oxfordshire (Oxford Health NHS Foundation Trust) and the Public Health Oral Promotion Service (delivered by Community Dental Services – Oxfordshire CIC).

Reporting to Buckinghamshire, Oxfordshire and Berkshire West ICB

A joint report of findings of the Core 20 Plus oral health focus across the Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board footprint will be presented at the (BOB ICB) Prevention and Population Health Committee in July 2024, jointly with Healthwatch Bucks and Healthwatch Reading. This will give an overview of findings from the three Healthwatch organisations and include a response from BOB ICB to our joint recommendations.

We encourage BOB ICB as commissioner of NHS dentistry in Oxfordshire to:

- Continue to support and raise awareness of Flexible Commissioning Scheme for improved dental access to support oral health and reduce inequalities of access experienced by Core 20 Plus groups.
- Support our recommendations below, within the remit of their commissioning functions.
- Continue to support Community Connectors approach as a way of ensuring voices of those with lived experience feeds into shaping of health and care services.

Feeding what we have heard at 'place' in Oxfordshire

This standalone report by Healthwatch Oxfordshire will be presented at 'place', to the relevant committees, including Oxfordshire Health

Improvement Board, Oxfordshire Health and Wellbeing Board, and Oxfordshire Health Overview Scrutiny Committee.

It will be shared with Oxfordshire Place Based Partnership, Oxfordshire Prevention and Health Inequalities Forum, and with Oxfordshire Parent Carers Forum.

Recommendations to stakeholders at 'place' in Oxfordshire

The **following recommendations** are made for the attention of key stakeholders at place in Oxfordshire including Oxfordshire County Council Public Health, Buckinghamshire, Thames Valley Community Dental Service - Oxfordshire (Oxford Health NHS Foundation Trust), Oxford University Hospitals NHS Foundation Trust, Community Dental Services CIC and Oxfordshire Local Dental Committee.

- For Oxfordshire Place Based Partnership to explore barriers and opportunities for joined up and system-led approaches to oral health across all partners, including information and support to families with SEND and vulnerable groups, as part of its priority on tackling inequalities in health.
- For Oxfordshire County Council Public Health and system partners to note what we have heard from families with children with SEND to inform development of next steps and action from Oxfordshire Oral Health Needs Assessment, early years support and within strategic focus on wider determinants of health, Health and Wellbeing Strategy, and to continue to work with the Public Health Oral Promotion Service (CDS CIC) to ensure a joined-up approach.
- For Thames Valley Community Dental Service – Oxfordshire (Oxford Health NHS Foundation Trust), Oxford University Hospitals NHS Trust and others to work to improve waiting times for community dental services and tooth extractions.
- For Oxford Health NHS Foundation Trust to explore providing oral health support to families whilst waiting both for tooth extraction, and within the Living with Neurodiversity Programme (https://onhs.autismoxford.com/), along with promotion and communication on referral pathways.
- For Oxfordshire Local Dental Committee to encourage review of awareness and training in oral health and SEND for NHS dentists and

oral health professionals – including advice on waiting room environment, resources provided, approach – with input from caregivers with lived experience.

For system partners together to:

- Note the insights of those with lived experience to inform practice, communication and planning, and embed into relevant service development.
- Review training in oral health across the system, including SEND support professionals, health visitors, early years, special schools, community paediatricians and other professionals supporting children and young people with SEND, ensuring information is tailored to need.
- Review information and resources available for SEND oral health support for families, and make improvements where necessary, seeking input from caregivers with lived experience.
- Clarify and promote Thames Valley Community Dental Service - Oxfordshire referral pathway to specialist support in appropriate places.
- Review coordination and provision of oral health support and uptake of Flexible Commissioning Service for asylum seekers and refugees, including those in hotel-based accommodation.

Next steps for Healthwatch Oxfordshire

Following our sharing event in April 2024, Healthwatch Oxfordshire agreed next steps of Core 20 Plus to build on work with Community Connectors and families supporting children with SEND to co-produce a leaflet or information pack, providing oral health guidance tailored to caregivers of children with SEND in Oxfordshire. We will work with Community Dental Service CIC Oxfordshire among others to support this development.

Background: Focus on Core 20 Plus 5 and Oral health

Why focus on children's oral health?

Having good oral health – healthy teeth and gums – is an important part of being healthy and well. Good oral health makes it easier to eat, speak and socialise confidently, and it reduces the risk of certain diseases.[1] It is seen as an important part of a child's health, including school readiness. Oral health is supported by things that prevent damage to teeth and gums, including healthy diet, regular brushing with fluoride toothbrush, and regular care for problems with teeth and gums by a health professional like a dentist or dental therapist. Most problems with teeth and gums are preventable, but inequalities in environment, access, experience and outcome persist.

Renewed focus and drive on tackling health inequalities and support to prevention of ill health has informed the NHS Core 20 Plus 5 Programme. The focus of this programme for children and young people is on oral health – and addressing the prevalence of hospital admissions for tooth extraction for under 10's.[2] The Core20Plus5 approach focuses on areas of the country that are in the 20% most deprived, according to the Index of Multiple Deprivation. 'Plus' includes focus on population groups facing additional inequalities including inclusion groups, people with a learning disability or autistic people and those who are vulnerable migrants. Within the NHS Core20Plus5 approach, an NHS Connector programme[3] supports organisations to recruit **'Community Connectors'** – people from the most deprived communities who want to take action to help reduce health inequalities in their local area. Different regions have built up shared learning with Community Connectors using approaches including

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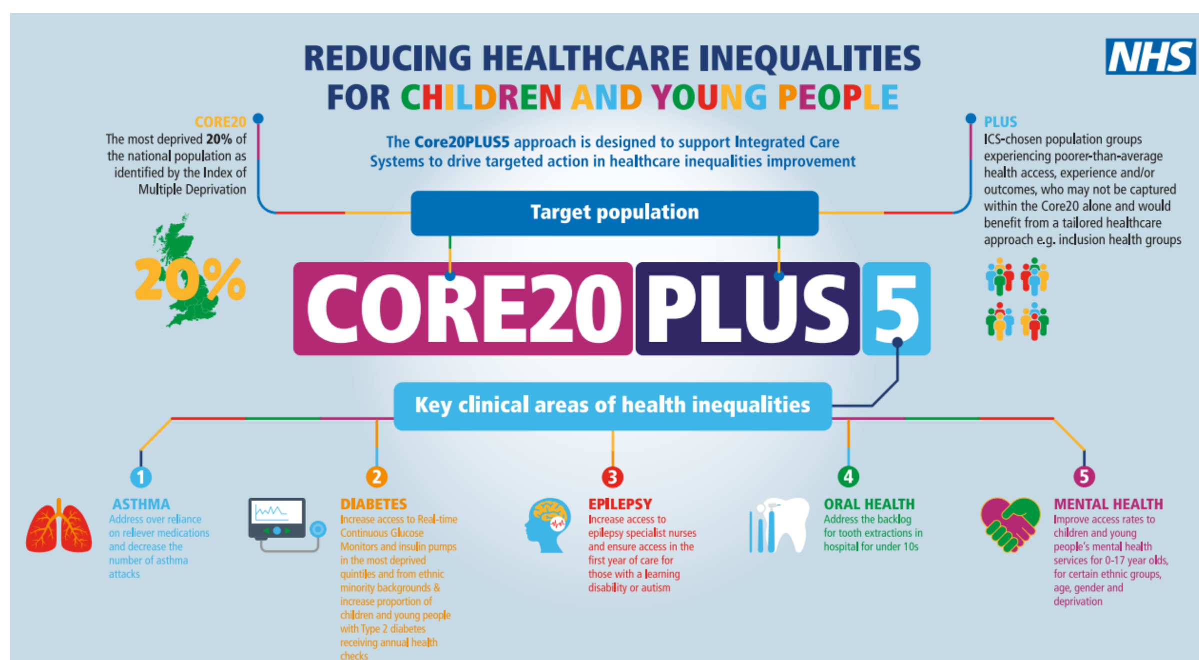
[1] https://www.dentalhealth.org/healthysmile

[2] https://www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/core20plus5/core20plus5-cyp/

[3] https://www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/core20plus5/core20plus5-community-connectors/

community research, co-production of new services and sharing information about health and wellbeing. Community Connectors bring lived experience and insight into health inequalities and use their own networks and relationships to build trust between communities and organisations to reach more people, including those from seldom heard communities.



Oxfordshire takes a Core 20 Plus focus. It has 17 areas in Oxford city, Banbury and Abingdon (known as LSOAs or Lower Layer Super Output Areas) that fall within the 20% most deprived areas in England. People living here have higher levels of poverty and often experience worse health, including oral health, than in other parts of the county. For example, in 2021-22, 18.5% of five-year-olds in Oxfordshire experienced tooth decay, better than the national average of 23.7%, whereas Oxford City (which has six areas in the 20% most deprived nationally) had significantly more children with tooth decay compared to the Oxfordshire and England average. In the same year, tooth decay was the most common reason for children aged 6-10 being admitted to hospital in Oxfordshire[4]. Children

[4] https://www.gov.uk/government/statistics/hospital-tooth-extractions-of-0-to-19-year-olds-2021
An estimated 90 children aged 6-10 had a hospital tooth extraction in 2020-21. Source: https://www.gov.uk/government/statistics/hospital-tooth-extractions-of-0-to-19-year-olds-2021

living in the most deprived communities needed tooth extractions due to tooth decay at three and a half times the rate of children living in the least deprived areas.[5] These areas may also be impacted more by wider determinants, including cost of living pressures, challenging food environments and limited access to affordable and healthy food choices[6].

Reaching seldom heard communities – the ‘Plus’ groups

The Core20Plus5 approach also recognises the ‘Plus’ groups who are more exposed to health inequalities. PLUS population groups include ethnic minority communities; inclusion health groups; people with a learning disability and autistic people; coastal communities with pockets of deprivation hidden amongst relative affluence; people with multi-morbidities and protected characteristic groups amongst others.

The ’Plus’ focus of this report aimed to hear from parents and carers of children with special educational needs and disabilities (SEND) and also reaching refugee and asylum seeking families living in hotel accommodation.

The Oxfordshire Oral Health Needs Assessment 2023 (Oxfordshire County Council) identifies children with SEND as a vulnerable group[7] but included limited experiences or voices from people with lived experience of caring for children with SEND. Hearing more from this group would ensure that implementation of next steps for oral health support can be guided by lived experience.

SEND comprises a wide range of needs and disabilities. These can include learning disabilities, learning difficulties, autism and other forms of neurodivergence, physical impairments, emotional needs and mental

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[5] https://insight.oxfordshire.gov.uk/cms/system/files/documents/OHNA_Oxfordshire_FULL_Sept23.pdf p.64

[6] https://insight.oxfordshire.gov.uk/cms/system/files/documents/HealthyWeightHNA_FULL_Apr23.pdf

[7] https://insight.oxfordshire.gov.uk/cms/system/files/documents/OHNA_Oxfordshire_FULL_Sept23.pdf

health conditions. A child is considered to have SEND if they require special support to meet their health or educational needs.[8]

Families seeking asylum may be housed in temporary hotel accommodation and face additional barriers to access, including language, support and other challenges.

What else is happening around oral health?

The Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB) Joint Forward Plan (2023), sets out delivery plans for improving health outcomes across the life course, including '*Start Well,* helping children achieve the best start in life', and a focus on a systems approach to obesity and unhealthy diet.[9] Oxfordshire Place Based Partnership priorities, the recently published Oxfordshire Health and Wellbeing Strategy (2024-30), Early Years strategy and other related plans also seek to address drivers of inequality in the county, including the things that contribute to poor oral health in children. Oxfordshire County Council published its Oral Health Needs Assessment in July 2023.

Local Healthwatch and Healthwatch England have responded to public concerns about limited and unequal access to NHS dentistry and continue to raise this with commissioners and providers at different levels within the system. For example, Healthwatch Oxfordshire reported on local dentistry in 2018 and 2021 and presented a 'Dentistry Mystery Shopper' to Oxfordshire Health Overview Scrutiny Committee in April 2024 which showed that of 57 NHS dentists we reached in the county, only 15 (29%) were taking children.

Services relating to oral health in Oxfordshire include:

- NHS dental services. These are commissioned by BOB ICB (https://www.bucksoxonberksw.icb.nhs.uk/your-health/dentists/)
- BOB ICB supports additional **flexible commissioning** to support dental access for some patients including those who have struggled to access a dentist, asylum seekers and refugees.

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[8] https://www.oxfordshire.gov.uk/residents/children-education-and-families/oxfordshire-send-local-offer/introduction-send

[9] https://www.bucksoxonberksw.icb.nhs.uk/integrated-care-strategy-joint-forward-plan/joint-forward-plan/

- Dentists offering private dental care or a mix of care.
- Oral health promotion and improvement services, delivered by 'Community Dental Services CIC' commissioned by Oxfordshire County Council Public Health. This offers training and support in oral health in different settings including early years through 'Healthy Smiles', and to groups such as health visiting, voluntary sector. (https://www.communitydentalservices.co.uk/oral-health-improvement/oxfordshire/)
- Thames Valley Community Dental Services - Oxfordshire, a partnership which includes Oxford Health NHS Foundation Trust. This provides specialist dental care to children and adults (for example with SEND, learning disability or phobia). This is delivered through nine clinics across Oxfordshire, as well as giving training and support, for example in special educational settings and to school nurses. This service can offer dental extraction in dentist surgeries for specialist cases. (https://www.oxfordhealth.nhs.uk/tvcds/service/)
- Oxford University Hospitals NHS Foundation Trust also provide specialist orthodontic and restorative dentistry, including hospital-based tooth extraction for children with extensive dental decay at the Horton and John Radcliffe Hospitals.

What did we do? Our methods

A BOB ICB wide approach tailored to 'place'

In September 2023, three local Healthwatch (Healthwatch Bucks, Healthwatch Oxfordshire and Healthwatch Reading) received NHS Core 20 Plus (Children and Young People) funding via Buckinghamshire, Oxfordshire and West Berkshire Integrated Care Board. We jointly took children's oral health as a priority. This enabled each Healthwatch to build both an overview, as well as develop local place-based Community Connector models, focused on our most deprived areas.

As noted, a separate joint overview report highlighting common themes and recommendations from the three Healthwatch organisations across

the area will be presented to the BOB ICB Prevention and Population Health Committee in July 2024.

At the start of this project, the three Healthwatch developed a shared approach. They jointly commissioned the Scottish Community Development Centre (SCDC) to provide three online training sessions for Community Connectors. These were delivered by SCDC in winter 2023, and videos of the sessions were made available afterwards for those who were unable to attend due to work and other commitments. These are now available as a public resource online (https://www.scdc.org.uk/oral-health). The training covered topics, including wider determinants of health, prevention, listening skills, confidentiality, safety, data protection and GDPR, gathering stories and making links – to build confidence in Connectors and enable discussion.

Recruiting, mobilising and training local Community Connectors
In developing its place-based approach, Healthwatch Oxfordshire focused on recruiting Community Connectors from Banbury Ruscote and Neithrop (two areas that fall in the 20% most deprived in England). We developed a role description and induction pack for Community Connectors and launched a call-out for Connectors via existing networks, our news briefing and social media. This was supported through active relationship building and in-person outreach at events, groups, community spaces, schools and dental surgeries in Banbury, including Sunrise Multicultural Project, Asian Women's Group, Sunshine Family Centre, Hanwell Fields Community Centre, Cherry Fields Primary, Hardwick Primary, Redlands Day Centre, William Morris School, Banbury Community Support Service, Ruscote Shops, Grimsby Community Centre, Brighter Futures Banbury, The Hill, Mum's Club, William Morris School, local dentist surgeries and Castle Quay Shopping Centre.

Healthwatch Oxfordshire's Engagement Lead held one-to-one meetings with interested people, to introduce them to the project and see if they wanted to become Community Connectors. Our aim was to recruit five Connectors. Two Connectors dropped out during the project due to other commitments, so we recruited a further two Connectors. Four of our five Connectors work at dental practices in Banbury, meaning that they

already had some interest in this area and were well-placed to signpost the people they had conversations with.

As well as this training, Connectors were given induction packs including information about the project and their role, guidance on obtaining consent and gathering stories and a set of questions about children's oral health to ask participants. Connectors had regular face-to-face meetings with Healthwatch Oxfordshire to give support and encouragement.

Following the training, from December 2023 to March 2024, Connectors had conversations with parents and carers from local communities about what it was like helping their children look after their teeth and gums.

They asked three simple questions:

- *What makes it easy to help your child to look after their teeth and gums?*
- *What makes it hard to help your child look after their teeth and gums?*
- *How do you find information to support you and is this easy to understand?*

All five Connectors made notes to record their conversations, along with additional insight about people's experiences. The five Connectors used their local heard from a total of 45 parents and carers via their local networks in Banbury Neithrop and Ruscote. Several Connectors went well above and beyond Healthwatch Oxfordshire's expectations – one Connector spoke with 17 people.

Throughout the process, Connectors were supported with regular one-to-one catch-ups to discuss progress and any barriers they were experiencing. Connectors were remunerated for their time with vouchers. Throughout the process, from recruitment to completion, a significant investment of time by Healthwatch Oxfordshire staff was crucial to the success of the project - building links with community organisations, developing relationships and trust with Connectors and supporting them through their training and insight gathering. Connectors reflected that they found the experience interesting and informative, but said that for them, the main thing is to make sure that people get the help that they need.

They also felt that members of the community were more likely to talk honestly to them and trust them more than health professionals.

Connectors were involved in identifying next steps and recommendations and presented their findings in a round table discussion in Banbury in April 2024 with key health commissioners and providers. This helped to jointly identify the recommendations and next steps for oral health.

A Community Connector sharing what they heard at our feedback event

Widening the reach

To supplement the work of the Connectors we launched an additional **online survey** to hear from **parents and carers of children with SEND** from across Oxfordshire. Additional questions were developed incorporating feedback from stakeholders with experience in oral health and/or SEND. The survey was shared through social media, our news briefing, in-person outreach, schools and early help mailing lists, and through support groups for parents and carers of children with SEND, including Oxfordshire Parent Carers Forum (OxPCF) and Autism Family Support.

In addition, we carried out **in-depth interviews** to hear in more detail from parents and carers of children with SEND. These included people who completed the survey and said they would be happy to share their story,

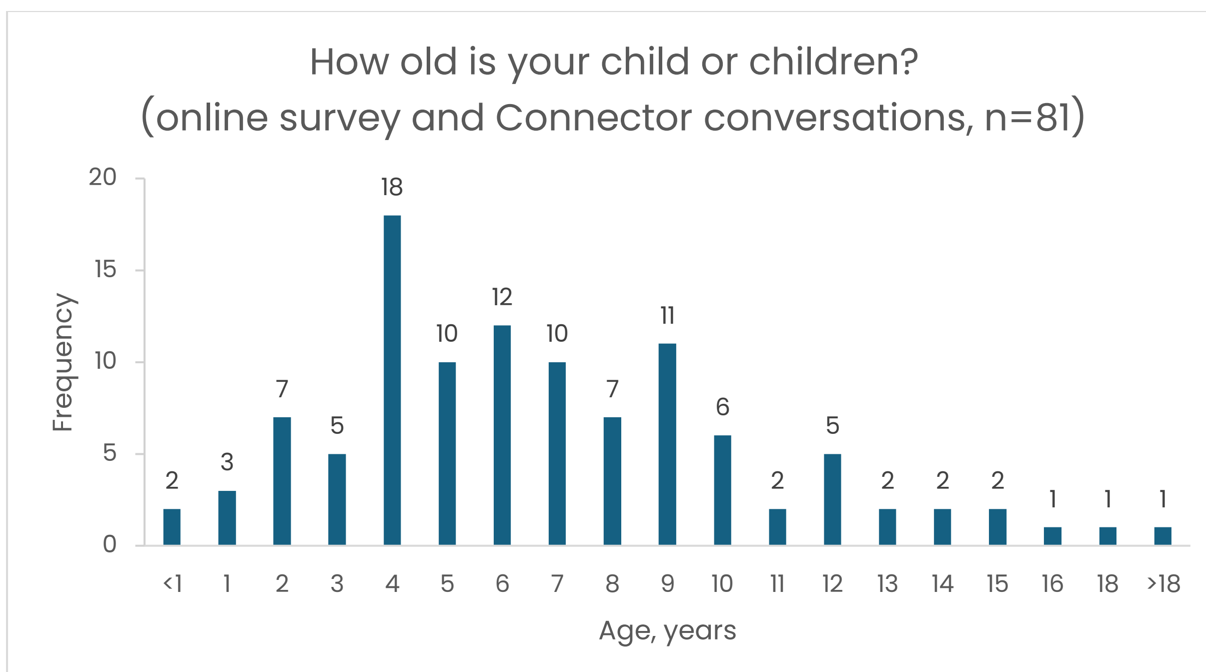
and people who were interested in becoming Connectors due to their personal experience but did not have time to take on the role.
We also attended outreach to two hotels in the Banbury area for asylum seekers and refugees, alongside the Community Dental Service - CIC.

Who did we hear from?

We heard from a total of **96 people**:

- **Via Community Connectors conversations: 45** parents and carers of 74 children in Banbury Neithrop and Ruscote. **31** of these parents and carers have children who have special educational needs and disabilities.
- Via the county wide survey: **38** parents and carers of 39 children or young people with special educational needs and disabilities, from across the county.
- Via In-depth conversations: **9** parents and carers of children with special educational needs and disabilities. (3 new and 6 of the 9 followed up via our survey).
- Around **10** parents and carers who are seeking asylum and who are temporarily housed in hotels in Banbury area. We visited together with the Community Dental Service CIC.

Most respondents had children aged between two and ten. Most of the people we heard from through the online survey were aged 20-49, women and White British. Connectors did not ask people their age and gender. They mostly spoke to people with White British ethnicity and a small number of people from other ethnic backgrounds. We heard from more people from Cherwell than any other district, which reflects the Connectors' focus and the higher level of outreach in the Banbury area for this project.



	Age	**Gender**	**Ethnicity**	**District**
Connectors' conversations (45)	Not collected	Not collected	38 White British, 1 British Indian, 1 British Pakistani, 1 Black African, 1 Mixed Black African and White	45 Cherwell
Online survey (38)	24 aged 25-49, 12 aged 50-64	33 women, 3 men	33 White British, 1 British Pakistani, 1 White Irish	10 Cherwell, 5 West Oxon, 8 Oxford, 3 South Oxon, 8 Vale

We heard from the caregivers of children with a wide range of special educational needs and disabilities in Oxfordshire. These included autism or Autistic Spectrum Disorder (ASD), attention deficit hyperactivity disorder (ADHD), sensory processing disorder, obsessive compulsive disorder (OCD), pathological demand avoidance (PDA), Tourette Syndrome, dyspraxia, anxiety, eating disorders and Down's syndrome. We also heard from caregivers of children who have not received a formal diagnosis but who have special educational needs or a disability.

What did we hear?

The themes of what we heard include both from Community Connector conversations, from survey and interview data. Where comments are used, the source has been noted.

What has helped you to support your child to look after their teeth and gums?

We asked people what has helped them to support their child to look after their oral health. People told us about things they have done themselves and help they have had from oral health professionals and schools.

We heard that caregivers **try hard to establish healthy behaviours, environment and incentives to support** children have good oral health. This included having **a routine, appropriate equipment, support and supervision, supportive environment and positive attitude**.

Things that caregivers have done themselves include:

- Having a good routine, especially for children with SEND.

  Letting him have some time before tooth brushing to regulate. (online survey)

  Watching a screen, and sitting in a comfy place while I brush his teeth helps (he spits into a plastic cup). I have to brush each quadrant of his mouth in the same order and in the same way every time. (online survey)

- Finding the right toothbrush for their child's needs – which might be an electric toothbrush, a Z-vibe, a soft-bristled toothbrush, a low-vibration electric toothbrush, a standard but familiar toothbrush or a three-sided toothbrush.

  It was difficult to brush his teeth, but my dentist recommended an electric brush and he gets very excited and loves chewing it! (Connector conversation)

  We tried many different types, some that he didn't like, others that were silicon and didn't brush his teeth well at all, and we finally settled on the collis curve. My son really likes it, and it

cuts down brushing time by two thirds due to where the bristles are placed (on three sides). This means he doesn't need the toothbrush in there for so long, and so there is less chance of him getting distressed. (online survey)

- Finding the right toothpaste for their child's needs – often a non-minty flavour and/or a non-foaming version, or high fluoride toothpaste.

  Prescribed toothpaste with more fluoride in it. (Connector conversation)

- Using a timer to encourage children to brush their teeth for two minutes.

  I try to keep them engaged with brushing with timers and flashing toothbrushes. (Connector conversation)

- Supervising brushing.

  Brushing their teeth separately, helping them, praising them (Connector conversation)

- Restricting sugary food and drink, for example making sure children only eat chocolate and sweets as an occasional treat or at weekends.

  I have learnt a lot recently they now drink water and occasionally drink squash. I do not buy sweets and cakes everyday and we are more focused on looking after teeth. (Connector conversation)

- Using videos, books, songs or communication aids (such as PECS) to explain why it is important to brush teeth and make it fun.

  Watching videos of people brushing their teeth and what happens when you don't. (Connector conversation)
  We watch the Peppa Pig episode where they visit the dentist and we re-enact it / play it out (online survey)

- Using sticker charts to encourage regular brushing or apps like Pokémon Smile to remind children to brush their teeth.

  Sticker chart for rewards when teeth are brushed properly (Connector conversation)

- Brushing teeth together as a family.

A recurring theme, especially from caregivers of children with SEND, was "trial and error": experimenting with different toothpastes, toothbrushes, routines, incentives and explanations to find a set-up that works for their

child. This often came with the knowledge that their child's needs might change in the future and they would have to work things out again.

> *With children with special needs, everything is trial and error, literally everything, pot luck, and something might like work for six months might then be completely different […] As a parent every child is different anyway, and we know that, and then with special needs, it's trial and erro.r* (interview)

External factors that supported caregivers to look after their children's oral health included:

- Good advice, from dentists, schools and other services (discussed in more detail below, under Information and support).
  > *Good information from dentists, eldest child had a school visit from a dentist which was good.* (Connector conversation)
- Support with healthy eating from schools.
  > *Schools also do healthy eating which helps.* (Connector conversation)

What makes it challenging for you to support your child to look after their teeth and gums?

We asked people what makes it challenging for them to support their child to look after their oral health. Responses from caregivers of children with SEND tended to focus on the impact of their child's needs.

What is it like helping a child with SEND look after their oral health?

Although the discussion here focuses on challenges, it is worth noting that for some caregivers, some aspects of helping their child look after their oral health were very positive.

> *He loves to visit the dentist and have his teeth checked. Likes to watch other family members do their teeth.* (online survey)

Caregivers told us about how some of their children's needs affected their ability to help their children look after their oral health. These included:

- Sensory needs and hyper-sensitivity.
- Demand avoidance.

- Learning disabilities or developmental delay affecting the child's understanding of why they need to brush their teeth.
- Limited motor skills or dexterity.
- Executive dysfunction making it hard for children to remember whether or not they had brushed their teeth.
- Limited attention span making it hard for children to brush their teeth for the recommended two minutes.
- Balancing these challenges with the child's wish for privacy or independence in their self-care.
- Looking after children with different needs.

People told us that children's **sensory needs** can affect their experience of brushing their teeth. In many cases we heard about, children find it hard to use standard toothpaste and need different flavours, flavourless or non-foaming toothpaste. They might also find the sensation of brushing distressing and need a special toothbrush or for toothpaste to be applied with a finger. Some children love the feeling of brushing their teeth. These needs can also change over time.

> *My son has sensory challenges so brushing can be uncomfortable/ painful, or it can feel pleasant and be a fun experience - every day varies.* (online survey)

We heard from parents that this can mean a lot of time spent trying out different toothpastes and toothbrushes, difficulty sourcing them and often a higher cost for specialty toothpastes and toothbrushes. Some caregivers told us they stockpile the toothpaste their child can tolerate, and one mum told us about trying to source a particular brand of strawberry-flavoured toothpaste from France or Canada when it suddenly became unavailable in the UK.

> *So, we've gone through several hundreds of thousands of toothbrushes. And several thousands of toothpaste. So we had to do the whole non… It's on Amazon, a toothpaste that has got no flavour, flavourless toothpaste, which is stupid expensive.* (interview)

For some families, sensory needs can affect their child's dietary preferences – for example refusing to drink water, or drinking milk from a bottle at night.

> *She doesn't eat food much because of her autism. So her bottle is her safety net. She keeps that in her mouth 24/7. And because she keeps the bottle it's sort of grinded away the front two teeth. So hence why, because she still has drank so much milk overnight, it ruins her teeth.* (interview)

Caregivers also told us about children who are sensitive to touch around their head or face, making it hard for them, or oral health professionals, to brush or examine their child's teeth. We heard from several parents whose children would clamp down or chew on toothbrushes, often destroying the toothbrush in the process.

> *My child is non-verbal and their understanding and cognitive abilities are far below his age. This makes it difficult to help them understand why I need to brush their teeth, or what to do if I give him the toothbrush himself. From a sensory point of view this makes it very difficult. My child is not keen on people touching his face, or other people putting things in his mouth. He likes to chew on all sorts of inedible objects, so when a toothbrush is put in his mouth he often just wants to chew it and clamps his teeth down on it, which obviously makes getting to brush his teeth a challenge. He is much happier than he used to be having his teeth brushed.* (online survey)

Demand avoidance – some autistic people may present with "*a persistent and marked resistance to the demands of everyday life*"' (National Autistic Society)[10] was also a defining feature of some caregivers' experience of looking after their child's oral health. Brushing teeth – whether being asked to do so independently or a caregiver trying to brush their child's teeth – can be experienced as a demand which the child resists. Some caregivers described tooth brushing as a "*daily battle*" of screaming and having to physically restrain their child in order to brush their teeth.

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[10] https://www.autism.org.uk/advice-and-guidance/topics/behaviour/demand-avoidance

[Child] doesn't let us always brush her teeth, you need two people to hold her down to brush her teeth […] We're now getting to a point where we just sneak toothpaste on her teeth while she sleeps instead of because yes, obviously she needs to brush her teeth, but then also how much I want to traumatise her, do you want to do it by physically holding her down to get to that point? (interview)

Needs, including sensory needs and demand avoidance, could also make experiences like going to the dentist stressful before the child even got into the dentist's chair – for example getting ready to go, making the journey, and waiting in a waiting room with bright lights, noise and nothing to do. We also heard that oral health professionals were not always good at supporting children with SEND or providing appropriate advice. (See section on Dental and oral health services for more detail about experiences of visiting the dentist.)

We heard from some caregivers of children with SEND who said that 'nothing was working' for them at the moment, especially around tooth brushing.

> *Reward charts do not work. Low demand is the only way forward at present* (Connector conversation)

> *We have been told by our specialist dentist that the best thing to do for individuals with special needs is try to prevent damage through diet and therapy to reduce manual damage to the teeth (through grinding).* (online survey)

Several caregivers told us that the financial cost of meeting their child's oral health needs was a challenge, for example the higher cost of specialist toothbrushes or toothpastes or getting through toothbrushes more quickly.

> *So, like a toothbrush will be £5.99 at least. And autistic children like you know, they would damage their toothbrush within five minutes. And then again, I have to go for a new one, again I have to go for a new one* (interview)

> *Do we follow the advice to change a toothbrush every six months or whatever it is? No, we don't because we try to make our money stretch. We definitely couldn't afford private dental care, that just wouldn't be an option as we live on one wage because I am their full-time carer. It feels to me like the gap is widening - those who are privileged are very able to afford it and those who aren't privileged just can't.* (interview)

For some caregivers, these costs are covered by their child's Disability Living Allowance. One caregiver noted that specialist, high-fluoride toothpaste used to be available on prescription, but they could no longer get it this way.

One parent also pointed out that, although caregivers try to keep their children healthy and well, there are often more pressing concerns for caregivers, particularly those of children with SEND, and oral health is often not the highest priority.

> *When you've got a child with autism and additional needs, probably teeth are probably quite far down the list of things to worry about.* (interview)

General challenges affecting everyone

We also heard about general challenges that affect people whether or not their children have SEND, although they might be made worse by challenges associated with SEND. These included:

- Existing dental problems making it painful to brush.

  > *My eldest son does not brush his teeth and won't let me, they hurt him as he has holes.* (Connector conversation)
  >
  > *Not easy, they all have bad teeth, I think they have weak enamel like me. They all have problems and don't like brushing very much. Even though I tell them to brush all the time.* (Connector conversation)

- Lack of knowledge and education about oral health.

> *I know I have messed up, but my family never bothered about diet and teeth either, so we are all learning now.* (Connector conversation)

> *I did not take her to the dentist for a long time and I did not realise you should when they were toddlers, by the time she went she had bad teeth and temporary fillings.* (Connector conversation)

- Managing children's sugar intake in the wider food environment.

> *My daughter is good at brushing her teeth but she does eat too much sugar. I think sweets and fizzy drinks are hard for parents to manage.* (Connector conversation)

> *Saying no and stopping relatives and friends from giving them sweets.* (Connector conversation)

> *I do worry how many sweets and coke she buys on the way to school.* (Connector conversation)

- Finding an NHS dentist and getting appointments.

> *I am a single parent, I work and have other children. I found it hard to find a local dentist when my child had a pain in the tooth* (Connector conversation)

We heard from several caregivers that they do not always have the time or energy to look after their child's oral health as well as they would like, particularly if their child is resistant to brushing their teeth or restricting their sugar intake.

> *Work - Sometimes I have an early or late shift starts and they can skip if their sister is not watching them brush their teeth.* (Connector conversation)

Sometimes I worry […] I have left it late in the day, after doing all the household chores. (Connector conversation)

It can be a struggle getting some children to eat well or brush their teeth. What should be a five minute task turns into 30 minutes to one hour. It can be draining, especially when still have lots to do around the house. Sometimes I give in, and he skips an important brush or gets to have a fizzy drink. (Connector conversation)

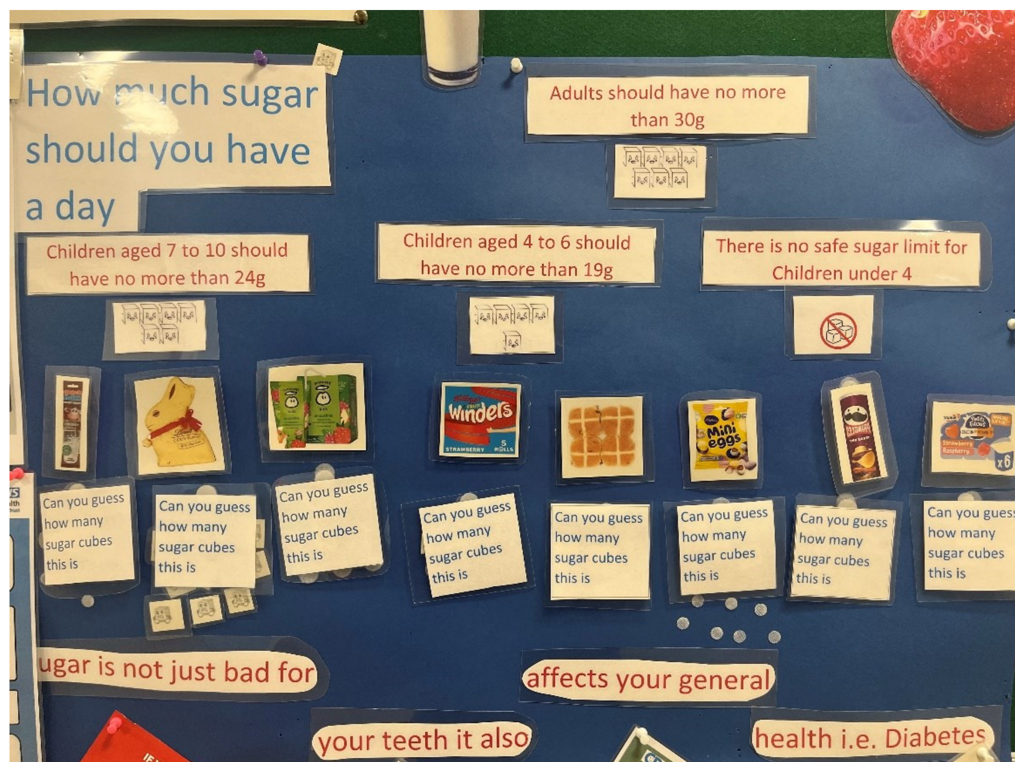


Photo of a sugar information board from a dental practice in Banbury

Family circumstances can also make it difficult for caregivers to put in place the conditions their child needs to look after their oral health. For example, one caregiver who is homeschooling their children said they found it difficult to access school nurses and health support. We heard from one parent about the difficulty maintaining a routine for their child due to co-parenting:

I have a 10-year-old little boy and because he's under SEND he has to have a solid routine. If he doesn't have routine, or if he breaks his routine, it's very difficult. Trying to get him to do something different or new in general is very hard. With his teeth, he has to brush them before he goes to bed and when gets up and has had his breakfast,

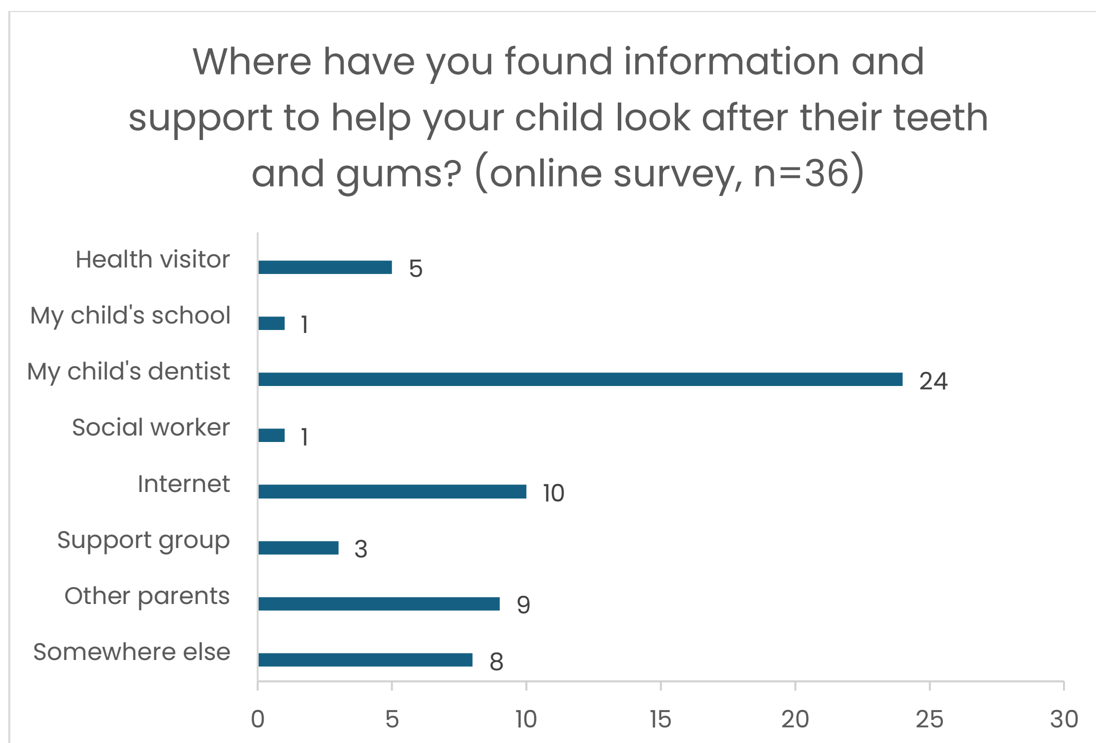
> *but it has to be done by a certain time for him to be happy. If he doesn't follow this routine, then it just doesn't happen. Me and his mum are co-parenting as we're no longer together and this disrupts this routine. Often when he comes back to me, I'm told that she's battled and tried to get him to do his teeth but hasn't because his routine has been broken.* (interview)

We also heard from a caregiver who was managing a complex life situation involving insecure accommodation, about the impact of this situation on looking after their child's oral health, both in terms of brushing their teeth and accessing dentist appointments:

> *From six months they start saying to you that the teeth are coming, so like start the tooth brushing for him. But he was not letting me touch his mouth. So like how can I do it? And I was also scared that they might think that I'm neglecting him or things like that.*
> *I was trying everything but he would not open his mouth. And he would not let me touch it. And he was a very big boy, And I would be scared that like, if he's hurt, like, you know, with the toothbrush, then they would be accusing me of hurting my child. Because I was already going through a lot in my normal life. So like because of that I was so scared. […} And with every change of place again he is referred to a dentist. So last time in [location] he was referred to a dentist. […] But I didn't get an appointment until like I was here. Now again, like he got an appointment [next month], but I cannot have it because again, I am moving.* (interview)

Information and support

People get information and support for looking after their child's oral health from a variety of sources. The most popular source of these was their child's dentist. Just over a quarter of caregivers who responded to the online survey found information and support on the internet, and a quarter got information and support from other parents, especially other parents of children with SEND. People who spoke to our Community Connectors gave similar answers to this question.



Other sources of information and support included health visitors or social workers, a community paediatrician, the Oxfordshire Family Support Network (OxFSN) health guide, the Ask Autistic Adults Facebook group, story books about going to the dentist, and lived experience from other people or the parent's own childhood.

> *The most useful advice has come from autistic adults - they have the lived experience.* (online survey)

One caregiver's response illustrates how multiple sources of support can work most effectively when they are combined: a professional did not have the relevant information but was able to help the caregiver access the information they needed using a website.

> *A professional (not a healthcare professional - worked for OCC) found some advice on the Oxfordshire Occupational Health website, that gave different options of things to try especially when brushing teeth is tricky from a sensory point of view.* (online survey)

36 of the 45 parents and carers who spoke to our Community Connectors (80%) said that the information they receive is helpful and easy to understand.

My dentist is very good also my health visitor gave me lots of support and helped me find a dentist. (Connector conversation)

Caregivers mentioned the key role that dentists and other oral health practitioners could play in supporting caregivers by educating children about the importance of good dental hygiene.

Good. Asked dentist to explain nighttime cleaning importance at last check up. Dentist gave son a leaflet explaining importance. (Connector conversation)

We heard that not all caregivers of children with SEND knew about the specialist community dentists, and that for many this was the first place they had got relevant advice.

Negative feedback about information and support was that it is not always tailored to children with SEND, it is often hard to put into practice, and it is not always received early enough.

Nowhere has provided information, I feel we are on our own in this. (online survey)

Not tailored to SEND unless I talk to other parents who I know have SEND children. Useful but no help specific to my child's issues. (online survey)

Diagnosis for my son took a while and help and advice for his teeth would have been helpful sooner - Since the diagnosis more information has been available and talking to other parents. (Connector conversation)

We also heard that advice was not always tailored to caregivers' different circumstances. For example, a single parent told us that advice about how to brush her child's teeth was based on having two adults.

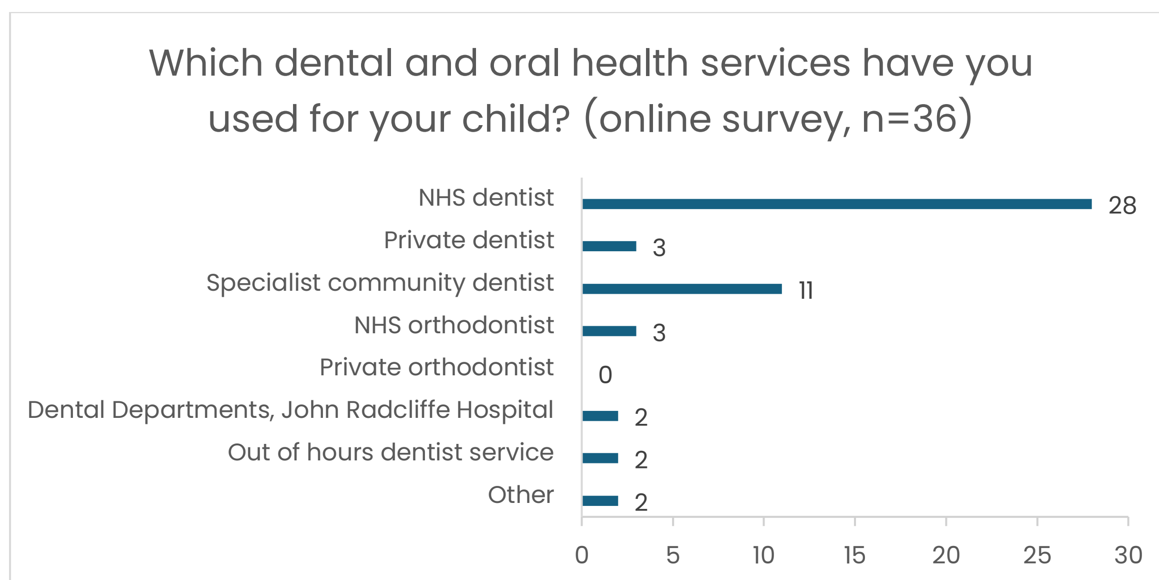
Several caregivers said they did not know that the guidance was to start taking your child to the dentist as soon as their teeth start to come

through. We also heard from two parents about conflicting guidance around milk. Milk is usually listed in oral health guidance as an acceptable drink for children, but in both cases, they felt their child's milk drinking had resulted in tooth decay.

> *I didn't realise when I was a first-time mother, just how much sugar there is in milk. So my daughter, when she first went to the dentist she had quite bad teeth because she used to drink milk through the night. I didn't know. No one put that in the parenting book and I think that's something they need, dentists need to put in the parenting book that there's so much sugar in milk.* (interview)

Dental and oral health services

Most of the people we heard from use an NHS dentist for their child. Just over a quarter of people who responded to the online survey said they use the specialist community dentist. Three people said they use a private dentist.



We heard that people face challenges finding an NHS dentist and getting appointments with them. These are common issues raised with Healthwatch Oxfordshire by the general public, but were particularly acute for the caregivers we spoke to. For example, the fear of being 'removed

from a dentist's patient list' is even more significant if a caregiver has finally found a dentist who their child is comfortable with.[11]

> *NHS guidance […] does not account for wait times. Our dentist cancelled their appointments and then they said the next available slots were 7 months away.* (Connector conversation)

When people manage to register and get appointments, challenges they told us about include:

- Having enough time in the appointment for the dentist to get the child comfortable enough to let them look in their mouth.

  > *No, they are very patient but the appointment times are too short for them to be able to examine properly*. (online survey)

- Dental practice staff not knowing how to support children with SEND.

  > *Showing patience and flexibility with methods different types of toothbrushes/toothpaste understanding that it is a real issue for them and it is not as simple as not wanting them to brush their teeth.* (Connector conversation)

  > *No adjustments made at NHS dentist so equipment, jargon used and understanding of neurodiversity lacked. They are frightened to go back.* (online survey)

  > *My daughter is very frighted by the dentist. The dentist just did things to her teeth without explaining it to her first. Seeing someone with a mask, a stranger is scary for her. Dentists are busy, but children with anxiety needs things explaining and time to build trust, before carrying out the dental work.* (Connector conversation)

- Lack of flexibility around appointment times

[11] Note that dentists do not have patient lists like GP practices, though this is a common misconception.

So long as we can book an appointment at the start of the day or just after lunch (i.e. 1pm) it is not too bad. (online survey)

- A lack of continuity of staff, for example at a training practice, meaning that the child has to get used to a new person and the caregiver has to repeat information.

Community dentist - not a good experience, different dentist every time, nothing in place to support children with SEN. (online survey)

- The waiting room environment being distressing for children with sensory needs or anxiety.

The year before COVID […] we tried to join a local NHS dentist but couldn't get in anywhere. The nearest one we could get into was over an hour away from home and that wasn't ideal. We all went as a family for the initial appointment, but they (the girls) had no preparation […] the girls were just frightened. It wasn't autism friendly; my children are frightened of dental equipment and the waiting room had pictures of medical equipment and scary images of gum disease and strokes etc… So it wasn't a very positive experience and they've not been back since which also has a huge effect on us as parents and dealing with that. (interview)

- Caregivers feeling shame around their children's poor oral health, and/or feeling blamed or judged by oral health professionals.

Stressful, she does not like the feeling. it is embarrassing for me as she has bad teeth and so stressful for my daughter and me. (Connector conversation)

We've also found dentists to quickly judge our situation say things like "they need to stop eating so many sweets" and things like that. In truth, my girls don't eat any sweets at all and are very fussy eaters and only eat planned meals. But you

do get those stereotypical judgemental comments. It was one particular dentist who made that comment without even asking what their diet was like and it was very off-putting. (interview)

We heard that people's experiences of dental and oral health services were much more positive when oral health professionals had sufficient time and patience to support the child to feel comfortable. This was more common at a specialist community dentist but caregivers also told us about good experiences of mainstream NHS dentists. Examples of good practice included having a series of monthly appointments to get children used to going to the dentist and working up to opening their mouth, dentists explaining every step to the child, and allowing the child to see and touch the different instruments.

What makes it easier is the support that I've been given from the children's dentist and the specialist dental nurse in Kidlington. She is very good, very helpful. She had a real approach. She just sat chatted to him and didn't make any attempt to touch his mouth whatsoever. She chatted, she gave him toothbrushes to play with, she gave him a little tiny mirror on a stick that you know a dentist would use just to play with. So of course, he was opening his mouth and then she's able to have a quick sneaky look in his mouth. It's all done with as little invasion as possible. He came out of there smiling and waving at her, so that was great. (interview)

Have total faith in his specialist dentist they are amazing and make it fun for him and are knowledgeable and supportive with the info they give me. (online survey)

We attend a SEND dentist, they are very supportive and patient, they book monthly appointments to help my son feel comfortable. (online survey)

Other comments we heard included a concern that children with particular needs were not unable to get access to X-ray treatment, and whether young people living in supported accommodation were having their teeth

cleaned properly, particularly as this was being done by different members of staff each time.

Tooth extractions

11 out of 45 parents and carers our Community Connectors spoke to in Banbury said that one or more of their children had had a tooth extracted. A further 3 said their children needed a tooth extraction and were waiting for treatment. Through the online survey, we also heard from 4 parents and carers of children who had had a tooth extracted. We heard that some families had had positive experiences of tooth extractions, for example in a community dentist setting where there was time to explain everything and support the child to feel comfortable. For some families the experience had been much more difficult.

> *[Two of my children had teeth extracted] and that was through the community [dentist] on Manzil Way, they gave them gas and air. That was quite fun. Both of them had one session on just how to inhale the gas and air, because they could not. Yeah, that was really fun to be fair. "Sniff it, inhale it! Dude, just do something!" But yeah, that was quite – not traumatic, I thought it was gonna be worse than what it was. Especially for [child] […] I thought she was going to freak out completely and they were so patient.* (interview)

> *My daughter had an appointment [at the John Radcliffe Hospital] in [month] to have her tooth extracted. The appointment was 45 minutes late and my daughter was getting very stressed waiting around. Appointments should not be delayed for autistic children.* (interview)

> *She needs 4 teeth taking out. The dentist could not do it, as she would let them as she was petrified of the needle. She was referred to the hospital. We spoke to the play therapist on the children's ward. She talked us through what would happen on the day. She saw how frightened my daughter was of the needles. She said they would draw up a plan. The Plan was we would bring my daughter on the day she would to the play therapist in the playroom. The dentist spoke to us. The anaesthetist came and talked to us, she agreed to give my daughter a sedative in her juice, then she was*

> *taken to theatre. My daughter would not let anyone touch her hands to get anywhere near her, so they decided to try a mask and sedated her- she would not let this happen. We were told we need to be stronger, it's hard when your child is crying saying she does not want to DIE. The procedure was cancelled. She still needs 4 extractions.* (Connector conversation)

What could be improved?

We asked people what could be improved to support them to look after their children's oral health.

We heard that people would like to see better access to NHS dentists, better funding of dentistry and greater continuity of dentists. Caregivers suggested that oral health professionals should be trained in supporting patients with SEND.

> *Well, the experience I've been through with my foster child isn't a rare experience. There are a lot of people out there with disabilities and special needs and there is not enough information about it. I don't even think the dentists are always well trained in this area because where I go, they've never heard of Oranurse toothpaste or these toothbrushes, it was only the specialist. I sometimes think that maybe the dentists could cover more of this in their basic training, and I think the same can be said for many other professions. Could there be top up modules or courses on special needs? Especially as autism and sensory issues are more common nowadays – really it should be part and parcel of all training across the board.* (interview)

People also highlighted that it would also be useful for SEND or learning disability support staff to have training in oral health, to make sure that everyone working with a patient understands their needs and how to help them look after their oral health.

Caregivers said that they would like to see more time for dentist appointments and other reasonable adjustments such as timing of appointments to avoid disrupting routine or the school day, or combining

dentist and hygienist appointments to minimise the number of trips to the dentist.

> *Putting extra measures in place for the initial appointment. For example if we have said our child has needs and severe anxiety, making effort to make adjustments and make that first appointment a happy one so they are feeling safe to come back.* (online survey)

> *Combine cleaning & check-ups in to the same appointments - it can be incredibly hard getting a child to the dentist & would be easier to do everything in one go.* (online survey)

> *Listen to the parent on what your child likes and dislikes and how they will react the certain situations. My son doesn't like being offered stickers, but loves to have a face mask and gloves so I take a set for the dentist to give him at the end instead of a sticker and helps to get him to sit down it's his reward even if it is a bizarre reward to them he thinks it's great and my dentist always obliges with his needs.* (online survey)

> *More time to explain things to children if they had time to do this, I believe my son would have been fine having treatment with his normal dentist.* (Connector conversation)

People suggested raising awareness among caregivers and professionals supporting them about the possibility of going to a specialist community dentist. Caregivers also mentioned more joined up working or improvements to the referral process to enable better access to specialist community dentists – particularly in the context of long waiting times for SEND diagnoses.

> *People like my daughter and those with similar needs need to be aware that they are able to use a community dental. They need to know they meet the criteria.* (interview)

> *NHS dentists need to know that they can refer children with special needs, especially children like my son of have far less understanding than another his age, combined with sensory difficulties with*

toothbrushing/ people looking in their mouth, to the Community Specialist dentist. Even if there isn't any decay or pain or other problem with the teeth. For those like my son, the NHS dentist couldn't even see inside his mouth so wouldn't know if there was a problem like that or not. When I spoke to the Community Specialist Dentist about what the first NHS Dentist had said about my son being referred to them, they informed my that that dentist was incorrect. They said my son is exactly the kind of patient they see, and that he is in the right place. Therefore more education needs to be given to NHS Dentists, so they can then follow the right advice and refer children more readily, as well as giving parents the correct information about referrals. (online survey)

We struggle to get support for our child and I feel that if all professionals were linked the child's needs would be identified sooner. Everyone struggles to get a dentist, I am always worried we will lose our place at our dentist. (Connector conversation)

Arrange automatic referral into community dentistry at the point of SEN diagnosis, especially if this is when they are young. (online survey)

More information needs to be available in GP offices about community dentists. More information about how you get a referral! (online survey)

Other popular suggestions included:

- Improving waiting rooms and treatment rooms to make them more accessible for people with sensory needs
- More, and more accessible, information for caregivers from pregnancy onwards, including information tailored to children with SEND and information about hidden sugars.

Step by step guide of how to teach tooth brushing and how to brush someone's teeth who is refusing (online survey)

- Providing more and/or improve access to resources for caregivers of children with SEND, such as adaptive aids and specialist toothbrushes

- Exploring the potential for home visits for children for whom going to the dentist is not possible.

  If I could dream anything it would be to expand healthcare to visits at home. Where it would be more accessible. (interview)

- Improvements to hospital waiting times for tooth extractions, particularly for children with SEND.

- Oral health promotion in schools and resources to help children to learn about taking care of their own teeth and gums.

  Also professionals visiting schools more and preschools to teach the kids brushing and oral hygiene in a fun but informative way would be really good. It will get the children into a good oral health routine from a young age. (online survey)

  Things aimed at children to engage them into the importance of looking after their teeth. Reward charts given at school information for parents. (Connector conversation)

- Making improvements to the food environment such as restricting the promotion and sale of fizzy drinks to children, and near schools.

- Working with and listening to caregivers

  Don't make the parents feel guilty, we already feel terrible that we can't force our children to look after their teeth and gums. We're doing our best! (online survey)

Appendix – note on oral health support to refugees and asylum seekers

As noted in the report, we made visits to speak to families who are seeking asylum living in hotel accommodation. Following this visit Healthwatch Oxfordshire convened a brief online roundtable discussion in April 2024 with commissioners, dental professionals, and local refugee support group to link up, share learning and link up towards a more joined-up approach around this group. Where information and support was being given the flexible commissioning scheme was proving successful. Building on insights from our own listening and from others the following barriers to oral health and access by refugees and asylum seekers to NHS dentistry and oral health support were identified:

- Limited knowledge and signposting to flexible commissioning scheme – although working well where was known – and possible gaps in this awareness in Banbury area.
- Delays and paperwork around HC2 forms.
- Limited understanding of charging for treatment, and ability to afford
- Language barriers/ not consistent interpreting support, or interpreters not being available for some languages e.g. Sorani, Tetum.
- Travel barrier.
- Clarity needed on ID requirements, some being turned away by dentists on grounds of paperwork need to support understanding of overall navigation of wider NHS services.

Following the meeting, the group will continue to link, and feed into the wider BOB ICB refugee health support network.

Appendix: stories

Story 1: “We’d leave with a smile on his face”
I have three children and they’ve all got different diagnoses. [R] has autism, ADHD and sensory processing. And it took me years to get him to the dentist. It's like just the thought of it would petrify him because the smells, the sounds, the bright lights, and it's quite... I don’t know, I struggle at the dentist, so I can kind of see where he was coming from. But there is a [community specialist dentist] and our dentist from Blackbird Leys referred us to there. Because [R] wouldn’t open his mouth and kind of just slammed shut his mouth and she was like yeah, he needs treatment and we're not going to be able do it here.

I highly recommend the community dentist for children with SEN needs. They're so patient. I think [R] went to six visits, it took six visits to get all the work he needed done, but they were so patient and they - we were never left leaving there feeling like ohh, we’ve been a pain in the arse. Nothing was too much for them. Like, even when you walk in the entrance, everything is a lot different to a normal dentist. It’s a lot calmer. All the lights, just like dimmed down. And I think just their approach, the way they speak, their mannerisms, explaining everything that they're doing, they're not just “open your mouth”, sticking this big, shiny thing into your mouth.

[R] got all his treatment, he's got silver plates put in, he thinks he’s Iron Man now! She said she was putting Iron Man caps on his teeth so the last few years he’s thought he was Iron Man’s stunt double. But it wasn’t easy and it wasn't done overnight. As I said I think it was six to seven trips we took with [R]. And it was good because they didn’t space them out too long. So I think we was there every week like 6-7 weeks, which I think was good. Like he didn't get over the trauma because it wasn't traumatic. But you know, that whole thing of oh, my God, this is happening. And he knew, the next week, what to expect, by that third or fourth week he’d kind of just get there, have banter with the dentist. He’s awful! He’d have banter with them and then just get his treatment done and then we’d just leave with a smile on

his face. I thought they were fantastic. But there’s such a long wait as well, isn’t there? I think we had to wait six months. So it was a bit of a wait, that's the only thing. Or they offer you Banbury as well, don't they? But if you can't commute, if you’ve got no transport, it's not always the easiest of things, that’s a lot of transport fees as well. But yeah, the community dentist is fantastic.

Story 2: “It comes down to how good your caseworker is”

Our experience has been really positive in Oxfordshire, originally we were in Buckinghamshire and every time we tried speaking to healthcare, there was no help or advice. We were just told to go to private clinics or sign up for an NHS doctor. We did that a couple of doctors, but they just couldn't cope with her. One of them was really rude, he was kind of like, come back when your daughter learns to behave.

When we moved here, we got in touch with the social worker, obviously to move [child]’s paper over. It happened straight away. We met with the health visitor, brilliant lady, she set it up with a health visitor and nutrition and everything so it was straightforward. And it wasn't long after that we got a referral to the community dentist. She's been there ever since.

She’s 5. She's still on a liquid diet. She doesn't eat food much because of her autism. Her bottle is her safety net. So she keeps that in her mouth 24/7. And because she keeps the bottle it’s sort of grinded away the front 2 teeth. And also she doesn't let us always brush her teeth, you need two people to hold her down to brush her teeth. So hence why, because she still has drank so much milk overnight, it ruins her teeth. We are now getting to a point where we just sneak toothpaste on her teeth while she sleeps instead of because yes, obviously she needs to brush her teeth, but then also how much do I want to traumatise her, do you want to do it by physically holding her down to get to that point?

It's just part of the job, right? It's just not much you can do, it's part of being a parent. Obviously with the added extra being an autistic parent it’s slightly different, but it’s still the same thing, right?

So the dentist, brilliant dentist, every time that he takes the time out to explain if there's anything that needs doing or what the outcome is. So information wise we get everything we need from him. And now obviously with her going with [special school], she has a paediatrician that monitors them, every three months, six months.

[Child] has an appointment to have teeth extracted at the JR. So it was picked up by the dentist and he made the referral and he’s following it through. So initially we thought we were gonna wait later, but no, it's about seven months, eight months from the moment it was referred to when it's going to be executed.
There's also her nutrition cause she is, as I said 90% on milk. She's quite picky with food. It can be anything from feel, look, sense. Yeah, it can be any of those three items. So she eats quite particular food and won’t always eat them. See this weird thing, she has a Turkish sausage called sujuk. If the taste is slightly off though, if the brand changes, she won't eat it. So with nutrition, other than giving her supplements and presenting her with food every day, there's not much you can do other than that. You can't force feed them. If it was medicine you sort of have to, but with food, there's no force feeding them. So she gets a pick of different choices. And then you just have to unfortunately supplement that with iron and [medication]. It only becomes a really issue if she's not putting on weight, or if she’s not growing and [child] is not having an issue with that. And then obviously with the downside of that is because she is on so much milk, then the teeth goes away, right?
With autism you learn that what is right one week might not be right next week and then it might be right again the third week. It’s trial and error. So like certain things just click, it can be anything from like the one week she doesn't like the way the doorbell sounds and the next week being fine with it. Yeah, you know it's real. People have this understanding that autism, oh they like routine, because we all seen that in the movie. That's not always the case.
It depends, it 100% all depends on their community health nurse or was it health visitor or whatever they call them. They're your main focal point, right? So like someone new with autism, their first protocol would be the midwife or the health visitor, whoever checks the baby first, right? That's surely who the knowledge should be exposed to. Obviously there's nothing when you Google autism and dentist or like there's nothing that will come up. Other than other experience with parents. Or you'll find one or two private clinic in London that specialise in it, but there's nothing like link. This is where you go. This is what you do in your county. It comes down to how good your caseworker is and how much knowledge she keeps.

Story 3: "It's all about routine"
I have a 10-year-old little boy and because he's under SEND he has to have a solid routine. If he doesn't have routine, or if he breaks his routine, it's very difficult. Trying to get him to do something different or new in general is very hard. With his teeth, he has to brush them before he goes to bed and when gets up and has had his breakfast, but it has to be done by a certain time for him to be happy. If he doesn't follow this routine, then it just doesn't happen. Me and his mum are co-parenting as we're no longer together and this disrupts this routine. Often when he comes back to me, I'm told that she's battled and tried to get him to do his teeth but hasn't because his routine has been broken. So, he might brush his teeth once at the very most during the week when he is at his Mum's.

But then, as soon as he's back into a regime with me, he knows exactly what he must do with his teeth. Sometimes though, even though he knows what he has to do, if it's not done it in a certain way, he really struggles.
It really is about having a solid routine. Myself, I also have to have a routine in my own day-to-day life because I suffer with OCD, and he as with any child needs to have a solid routine to be able to function properly shall we say. Otherwise, you're all over the place and as soon as he's all over the place then the day becomes a write off. A stable routine is what he needs. With no let-up, if that makes sense. If he breaks his routine and if he feels that he can't do what's expected, like brushing his teeth or washing his face. He got a certain way that he brushes his teeth, but if he's not done it within the routine, i.e., 'his way' then he won't do it. So, it's it is literally again, all about routine. He's got a specific routine of the way he does his teeth like the timings and directions and things like that. If he doesn't do it, then he'll worry all day.

He's fine going to the dentist. Obviously, he knows about teeth and stuff. He knows what the dentist says to him about hygiene and that he has to brush his teeth for a certain amount of time etc... Like with most kids, they just want to get it over and done with and get on with what they want to do.

But with him, he's had to have, I think two fillings. Because either genetically, his teeth aren't particularly good like both parents, but also with where he hasn't got the consistency of looking after his teeth. The dentists do try and

encourage him and he’s great when he’s in at the dentist and nods and is like “yeah, yeah, yeah, I'll do it like this and that, blah, blah…” But then as soon as he leaves the situation of the dentist and he's back home then he has to be in routine to be able to do it.

For me it’s all about routine and I think children need more of knowledge and understanding about teeth and dental hygiene. I think this should be taught more in schools, I also think it would be useful if schools were to supply children with toothbrushes, especially the ones that need it. Because a lot of children have limited access to things like this during hardship. Obviously, my little boy is lucky because all of us work and stuff but there are a lot of parents out there that can't afford the expert bits and pieces you know. So, I think encouragement such giving children a toothbrush and toothpaste take that home if needed, for instance, would provide encouragement.

Story 4: “that choice has been taken away”

I have two children so I will talk about both. Both are autistic; one of them has been formally diagnosed and the other one not. They both have mental difficulties/delay in some way and communication difficulties, as well as high sensory processing difficulties and hyper-mobility and it is hard looking after their teeth. For one of them it is a routine, and she likes the routine of brushing teeth - so that's easier and one battle won. My other child, however, is only able to brush her teeth maybe once or twice a week… maybe three times if we are lucky. A year or so ago we were really panicking over that. But now that has kind of become the norm because we're understanding her needs a bit more.

I think things like kids’ toothpastes help. I know that sounds basic, but just having a variety of toothpastes and toothbrushes to try. Because with autism, the sensory difficulties that come with that can be really hard. You can get all sorts on the Internet now, different brushes and things like that. Our girls actually prefer just a plain plastic toothbrush. One of them uses toothpaste that probably isn't age appropriate any more and could do with using an older one but it's difficult to move them onto new products. So, we tend to bulk buy their toothpaste if we see it because running out wouldn’t be good. One of them only likes Sensodyne childrens toothpaste.

We’ve also tried all sorts of all sorts of apps like Pokémon Teeth brushing and other kid’s apps. Also, things like a reward chart, but we’ve found that that puts too much added pressure on them.

Dentists have not accessible to us in our current situation which is that our children have been unable to leave the house for about a year. They go to the park and their favourite places but going to new places is a huge challenge. They both require one-to-one support which makes it difficult to get them to go anywhere. I think that's the biggest challenge and also the fear of seeing a dentist. I also think they’ve suffered a lot because of COVID due to not seeing anyone and I think that’s had a massive effect on children and them feeling comfortable around medical professionals.
The year before COVID, we moved into our house, and we tried to join a local NHS dentist but couldn't get in anywhere. The nearest one we could get into was over an hour away from home and that wasn’t ideal. We all went as a family for the initial appointment, but they (the girls) had no preparation. It was a really small private, old looking dentist with one room and the owner was a bit old and the girls were just frightened. It wasn’t autism friendly; my children are frightened of dental equipment and the waiting room had pictures of medical equipment and scary images of gum disease and strokes etc… So it wasn't a very positive experience and they've not been back since which also has a huge effect on us as parents and dealing with that.

The prices have definitely gone up, but we manage. Do we follow the advice to change a toothbrush every six months or whatever it is, no we don’t because we try to make our money stretch. We definitely couldn't afford private dental care, that just wouldn’t be an option as we live on one wage because I am their full-time carer. It feels to me like the gap is widening - those who are privileged are very able to afford it and those who aren’t privileged just can’t.

Both me and my husband, used to be able to afford private dental care before children and that was a more positive experience because I think we could be choosy, and you could choose the right place. We no longer have that choice. That choice has been taken away.

I'd like to try and advocate for people with autism and how hard it is to get out of the house for them. I think expanding healthcare…. If I could dream anything it would be to expand healthcare to visits at home. Where it would be more accessible and also to lower expectation as there is a lot of shame, misinformation and lack of training when it comes to autism.
We've also found dentists to quickly judge our situation say things like "they need to stop eating so many sweets" and things like that. In truth, my girls don't eat any sweets at all and are very fussy eaters and only eat planned meals. But you do get those stereotypical judgemental comments. It was one particular dentist who made that comment without even asking what their diet was like and it was very off putting.
I think dental visits at home would make dental care more accessible, especially for people like us who are homeschooling. Homeschooling it makes it even harder to access healthcare, even the school nurse team – they say that your child will still be able to access those spots, but in reality, our experience has taught us that this isn't always the case. For example, in the past year when we've tried to get bladder help and medical help, we've found it a real challenge and home schooling has been the reason.
A lot of them say OK, we need to put them back into school and then we'll be able to help, which isn't an option for us. We home school because there wasn't enough medical support so that is a huge challenge.

We tried to access the Community Dental Service which is supposed to be more sympathetic, and they were very understanding when we called up and explained that we weren't able to get to them which was good, but we still haven't seen them. This is the point where we feel unheard as I am telling them that we can't get to them because my daughter can't go to the dentist as the actual place is very scary for her. So what interventions are in place? What therapy is there available in order to get my children to a point where they don't feel frightened of doctors, dentists, police…? You know, I feel like there is a lot of parental blame, at least that's what we've found anyway.

Helpful links

- Oral Health Information Hub – for Parents, Teachers, Professionals and Children https://www.communitydentalservices.co.uk/oral-health-improvement/family-fun-information/

- Oral Health toolkit (Easy Read) https://oralhealthtoolkit.co.uk/

- Thames Valley Community Dental Services https://www.oxfordhealth.nhs.uk/tvcds/

- Leaflet: Oral Health Advice for Parents of Children with Autism https://www.bspd.co.uk/Portals/0/BSPD%20Advice%20for%20parents%20of%20children%20with%20autism%20Jan%2017.pdf

- A Parents' Guide to oral health and dental care for children with a learning disability, autism or both https://contact.org.uk/wp-content/uploads/2021/03/a_parents_guide_to_dental_care__web_single.pdf

- Oxfordshire Family Support Network https://www.oxfsn.org.uk/

- Oxfordshire Parent Carers Forum https://www.oxpcf.org.uk/

- Dentists https://www.bucksoxonberksw.icb.nhs.uk/your-health/dentists/ and flexible commissioning scheme

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