healthwatch Bucks healthwatch Oxfordshire healthwatch Reading

Supporting children's oral health

Experiences of parents and caregivers of under-10 children

A report of findings from Healthwatch Bucks, Healthwatch Oxfordshire and Healthwatch Reading

June 2024

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Executive summary

In September 2023, Buckinghamshire, Oxfordshire, and West Berkshire Integrated Care Board (BOB ICB) funded three Healthwatch (Healthwatch Bucks, Healthwatch Oxfordshire and Healthwatch Reading) to undertake a community-based research project to understand some of the challenges that parents and caregivers face when looking after the oral health of children under 10-years-old.

The project was supported through the **Core20PLUS5** Connectors initiative, a national NHS programme working to reduce health inequalities.[1] One arm of the programme seeks to reduce oral health inequalities for children and young people.

The three Healthwatch teams each recruited and trained five 'Community Connectors' – local residents interested in local health issues and with connections to their communities, and living in an area identified as deprived.[2] They interviewed parents and caregivers in their community about their children's oral health. In addition to local insight gathering, the Community Connectors presented findings and participated in the formulation of recommendations for local stakeholder organisations and BOB ICB.

Together the Healthwatch projects heard from a total of 215 parents and caregivers, relating to their experiences of supporting oral health care to 271 children. Participants represented a wide range of demographic characteristics and included parents and caregivers of children with and without special education and needs and disability (SEND).

Main findings

Children's oral health

- Parents and caregivers said they were involved in their children's oral health, including supervising brushing, checking teeth and gums, and brushing their teeth.
- Most parents and caregivers said they had an awareness of the risks of poor brushing and of consuming too much sugary food and drink.
- Many were concerned about their children's teeth and gums as well as being able to access dental care when they needed it.

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

[2] The communities were identified using the 2019 English Indices of Deprivation (IoD), a measure of relative deprivation at local level based on seven domains: income; employment; education, skills, and training; health and disability; crime; housing and services; and living environment (see https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019).

What helps families support their children's oral health?

- Three broad areas of support helped (where available) parents and caregivers care for their children's oral health:
    - **Behavioural support** – teaching good oral health using educational resources (e.g. games, videos, songs, television programmes), positive routines, and watching siblings or parents brush, rewarding good hygiene, and supportive supervision.
    - **Practical** – including buying special toothbrushes and toothpaste, using timers for brushing, brushing together as a family, reducing sugar intake, and being flexible with brushing routines.
    - **Professional** – getting information and advice from dentists, health visitors in the early stages of child development, their children's school, and through healthy eating at school.

What challenges do parents and caregivers experience in supporting children's oral health?

- Parents and caregivers faced challenges in four main areas:
    - **Awareness and education** – gaps in knowledge and understanding of oral health and dentistry services, lack of information and advice, including tailored information for families with children with additional needs.
    - **Behaviour and practice** – including children's resistance to brushing teeth, sensory issues and limited dexterity of children with additional needs making it difficult for them to tolerate brushing or dental treatment.
    - **Family and caring** – challenging family and personal circumstances, difficulty managing their children's diet and sugar intake, and the need to buy special toothbrushes and toothpaste.
    - **Access to dental care** – finding and registering at a dental practice, getting an appointment, language barriers for people whose first language is not English, and options for families with children with additional needs.

Access to dental practices and appointments

- Most parents and caregivers said they had registered their child or children with a dentist and most children had visited a dental practice twice or more in the past year.
- However, some children were not registered and several had not recently been seen by a dentist.

- Families said they found it difficult to find a local NHS dentist to register their child or to get treatment for a dental problem.
- Parents and caregivers of children with additional needs found it particularly difficult to find dental care that met their child's individual needs. Not all of them knew about alternative support such as community dental services.
- Parents and caregivers had mixed experiences of getting dental appointments. Some experienced long waits or unavailability, cancellations, emergency-only appointments, and inflexible booking times.
- Parents and caregivers recognised that the Covid-19 pandemic had affected the availability of appointments.

Experience of visiting the dentist

- Parents and caregivers were mainly positive about their children's visits to the dentist.
- Positive experiences focused on dental staff giving useful advice, clear explanations, and having a child-friendly approach.
- Parents and caregivers of children with additional needs valued dental practices where staff understood neurodiversity, accommodated their children's needs, and provided supportive care.
- Negative experiences included environments that were not SEND-friendly, insufficient appointment times or delayed/cancelled appointments, and frequent changes of practice staff.

Suggestions for improving support for children's oral health

- Parents and caregivers offered many suggestions they felt would improve children's oral health. These broadly focused on:
    - Expanding oral health education and information to all children and adults, including advice for supporting children's dental care and home, and tailored information for parents and caregivers of children with additional needs.
    - Oral health promotion activities aimed at healthier food, oral health in schools, and better oral hygiene practices.
    - Increasing availability of NHS dentists and appointments.
    - Promoting awareness and a SEND-friendly approach in all dental practices.
    - Integrating services to encourage collaboration between health and non-health professionals.

- Improving access to language and translation support for people whose first language is not English, including written materials and interpreting services.

Recommendations

This report contains two levels of recommendation. Firstly, those in the following list (and in **section 7**) are intended for BOB ICB in the planning and provision of publicly-funded dental services across Buckinghamshire, Oxfordshire and Berkshire West. Secondly, **Appendix 1** comprises a set of locally-specific recommendations taken from the individual reports produced by Healthwatch Bucks, Healthwatch Oxfordshire, and Healthwatch Reading.

This report will be presented to BOB ICB Prevention and Health Inequalities Committee for discussion and action.

Recommendations for BOB ICB

1. Inform and encourage local place-based stakeholders to review individual Healthwatch reports, taking special note of the findings and recommendations for each area (see **Appendix 1**).
2. Review and promote initiatives in educational settings of all levels to ensure that children learn about oral health and practice good dental hygiene (e.g. provision of educational resources and supervised brushing).
3. Continue efforts at reducing oral health inequalities, including:
   - Enhancing existing BOB ICB strategies – such as **Start well** – that support families and communities to ensure their children achieve good oral health.
   - Commissioning or supporting community oral health improvement interventions in deprived communities that raise awareness of oral hygiene and help parents and caregivers make informed choices about their children's oral health.[3]
   - Continuing to support and raise awareness of the Flexible Commissioning Scheme to improve access to oral health care for groups who have been unable see a dental practitioner or have recently moved to the area.
   - Further developing initiatives such as the Community Connector model as a valuable means of engaging with communities and hearing about local people's experiences of oral health, as well as building trust and increasing reach.

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[3] See for example: https://www.nice.org.uk/sharedlearning/feeding-your-baby-sessions-to-deliver-oral-health-messages#key-learning-points

- Linking with organisations that work with communities experiencing health inequalities to better understand their needs and experiences, and as an opportunity to increase awareness of oral health and local dental services.
- Ensure the provision of accessible interpreting services and translated written materials for families whose first language is not English.

4. In line with the BOB Integrated Care Partnership (ICP) **Integrated Care Strategy** of supporting children and young people with additional needs, emphasise the adoption of SEND-focused approaches to oral health. For example:
   - Explore ways to provide accessible, tailored information, advice, and support to more parents and caregivers of children with additional needs, including how and where to access to community dental practices.
   - Expand tailored, culturally sensitive training for dental and allied professions on the needs of SEND children, including involving people with lived experience to support the process. Training should adhere to the Oliver McGowan Mandatory Training on Learning Disability and Autism[4]
   - Promote activities and events for oral health professionals (perhaps involving other health professionals with relevant knowledge and experience) based on shared learning and skills building. Examples might include seminars or 'lunch and learn' sessions.
   - Link and collaborate with local groups and organisations that support children with additional needs.
   - Encourage greater engagement between parents/caregivers and local dental services with a view to increasing understanding of the barriers and facilitators to children's oral health, building relationships between families and practice staff, and facilitating a partnership approach to oral health provision.[5]

5. Using a multidisciplinary approach, continue a policy of sharing and building on current good practice, especially regarding the provision of

[4] https://www.hee.nhs.uk/our-work/learning-disability/current-projects/oliver-mcgowan-mandatory-training-learning-disability-autism
[5] Ideas from the Patient Participation Group (PPG) model at GP practices might be explored. See: https://napp.org.uk/for-patients/

SEND-friendly services, involving dental staff, health visitors, and other health professions.

6. Improve referral pathways to community dental services, including:
   - Providing clear information to parents and caregivers about available services, how to be referred, and self-referral.
   - Reviewing referral waiting times between dental practices and community dental services.

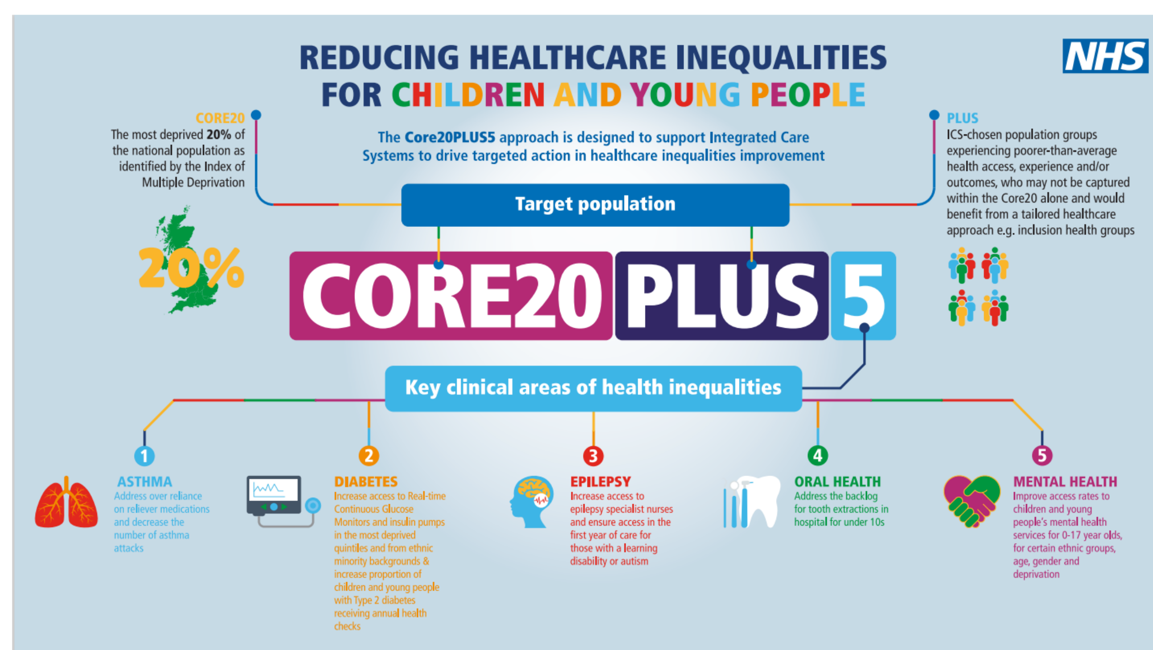
The findings from this report will be presented to the BOB ICB Local Dental Network and to the Prevention and Health Inequalities Committee in July 2024, and will be shared with local public health and other stakeholders in each of the three project areas. It will be available on each of the three Healthwatch websites where the individual reports will also be published. A short summary document and easy-read version of the report will also be available.

1 Background

This report summarises the findings of three projects completed by Healthwatch Bucks, Healthwatch Oxfordshire, and Healthwatch Reading on the experiences of oral health among parents and caregivers[6] of children under 10 years of age.

In September 2023, the three Healthwatch received funding as part of the NHS **Core20PLUS5** (Children and Young People) programme[7] via the Buckinghamshire, Oxfordshire and West Berkshire Integrated Care Board (BOB ICB). **Core20PLUS5** is a national NHS England approach aimed at reducing health inequalities. It was recently adapted to include system change and improve care for children and young people. One of the five areas of focus of the **Core20PLUS5** programme is children's oral health (see **Figure 1** below).

Figure 1. NHS Core20PLUS5 approach to reducing health inequalities for children and young people



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

Oral health problems among children continue to be an important health problem in England. In a recent survey of year-6 children (aged 10-11) in mainstream, state-funded English schools by the Office for Health Improvement and Disparities National Dental Epidemiology Programme (NDEP), 16% of

[6] For consistency, this report uses the term 'parents and caregivers' to refer to anyone in the three Healthwatch projects with responsibility for looking after one or more children.
[7] https://www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/core20plus5/core20plus5-cyp/

participating schoolchildren had experienced tooth decay.[8] A similar NDEP survey found that more than 29% of 5-year-olds in England had experienced any form of tooth decay.[9] Analysis by the Royal College of Paediatrics and Child Health (RCPCH) has shown that tooth decay is the commonest reason for children aged between five and nine years to be admitted to hospital.[10]

Poor oral health can affect children's ability to eat, smile and socialise, and can cause pain and infection. Oral health problems are preventable, mostly through a healthy diet and good oral hygiene. However, it is also closely related to wider social determinants, such as socioeconomic status, education, and housing. Children from poorer families and certain ethnic groups experience more and worse oral health than other children. For example, the NDEP survey found that schoolchildren in the most deprived areas were more than twice as likely to have experienced tooth decay compared with those in the least deprived areas. Prevalence of tooth decay was also significantly higher in Asian or Asian British ethnic groups and those who identified as 'other ethnic group' than other groups. [4]

Data from the NDEP survey[4] for the BOB ICB region show that the percentage of children aged 5 years with any experience of tooth decay is 19.3%, lower than the national average. However, considerable inequalities exist across the region. For example, at the Lower Tier Local Authority (LTLA) level, the percentage of children aged 5 years with any experience of tooth decay was only 16.5% in Oxford compared with 32.9% in Reading.

Primary oral health care is provided through a variety of general dental practices and orthodontist services. Children with special educational needs and disability (SEND)[11], who are unable to receive care from a general dental practitioner but do not necessarily hospital treatment, can be referred to the Community Dental Service (CDS) at the Oxford Health NHS Trust.[12] BOB ICB has also established the Flexible Commissioning scheme whereby dental practices can allocate some of their working time to see patients who have not recently had a dental consultation or are new to the area.[13]

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[8] https://www.gov.uk/government/statistics/oral-health-survey-of-children-in-year-6-2023/main-findings-of-year-6-oral-health-survey
[9] https://www.gov.uk/government/statistics/oral-health-survey-of-5-year-old-children-2022/national-dental-epidemiology-programme-ndep-for-england-oral-health-survey-of-5-year-old-children-2022
[10] https://stateofchildhealth.rcpch.ac.uk/evidence/prevention-of-ill-health/oral-health/
[11] While recognising the diversity of SEND characteristics, for brevity and consistency the remainder of this report uses the broad term 'children with additional needs'.
[12] https://www.oxfordhealth.nhs.uk/service_description/dental-services/
[13] https://www.bucksoxonberksw.icb.nhs.uk/your-health/dentists/

2 Methods

This section describes the methods used in this joint report and briefly outlines the approach taken by the Healthwatch oral health project teams.

The work for this report was carried out by an independent consultant trained in health research and qualitative methods. Each Healthwatch provided a copy of their project report and some additional documentation, such as Community Connector feedback forms and notes of conversations with selected Community Connectors.

The researcher examined each report for information about the background to the work, approach and methods used, key findings, and recommendations. Key findings from each report were organised according to the questions that Community Connectors asked the local community, then compared to identify similarities and differences. The combined findings were written up and parent/caregiver quotes were taken from the relevant Healthwatch report(s) to provide illustrative evidence.[14]

The documentation on Community Connectors' experiences of the project were reviewed and discussions were held with a small number of Healthwatch programme staff to reflect on aspects of the model and to propose some considerations for future implementation.

2.1 The Healthwatch projects[15]

Each Healthwatch project selected three areas with higher levels of deprivation in their county in which to implement the Community Connector approach. They were:

- **Healthwatch Bucks:** Aylesbury, Wycombe, and Chesham
- **Healthwatch Oxfordshire:** Banbury Neithrop and Ruscote
- **Healthwatch Reading:** Norcot, Church, and Southcote

2.1.1 The Community Connectors approach

Each Healthwatch project recruited five Community Connectors whose role was to explore the lived experiences of parents and caregivers of children under-10 years old in their communities about their experiences of children's oral health

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[14] Many of the quotes from Healthwatch Reading originate in their primary data rather than their report.

[15] For more information, refer to individual Healthwatch reports (links are provided in section 8).

and access to dental care. Selection criteria varied slightly between each Healthwatch but, as a minimum, required the Community Connector to be:

- Living in a Healthwatch oral health project area identified as having higher levels of deprivation
- Local knowledge and connections in their communities
- Interested and willing to hear from local parents and caregivers about their experiences of supporting children under 10 with their oral health
- Able to communicate effectively with local people in English and other languages (e.g. Arabic, Hindi, Urdu or Pashto) if required

Healthwatch Bucks aimed to recruit parents and caregivers of children around the age of 10 years, while Healthwatch Reading recruited people with backgrounds in pharmacy, general practice, social care, and public health so that they could provide families with useful information and advice.

The Community Connectors received online training commissioned by the Healthwatch groups from the Scottish Community Development Centre (SCDC). The training covered confidentiality, safety, data protection and GDPR, story-gathering, and making links with communities.[16] Each Healthwatch also provided community connectors with internal training and ongoing support. For example, Healthwatch Reading provided their Community Connectors with training and practice on conducting interviews.

The Healthwatch project teams developed a set of interview questions to help Community Connectors conduct their interviews. Healthwatch Bucks and Healthwatch Reading involved their Community Connectors in the development of these questions to capture their local knowledge and experience. Between December 2023 and March 2024, each Community Connector was tasked with interviewing at least five parents and caregivers of children under 10 years old in their local communities, usually at the participant's home or at a community centre, or online. They all spoke to families of children with and without additional needs.

Healthwatch Reading Community Connectors conducted in-depth face-to-face interviews with 25 families from ethnically diverse backgrounds. Each interview lasted between 45 to 60 minutes, in which Community Connectors were able to gather valuable insights into people's experiences in ethnically diverse communities.

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[16] For more information, see https://www.scdc.org.uk/oral-health

Some Community Connectors exceeded the five interviews – one in Oxfordshire spoke with 17 local people. Besides interviewing, Community Connectors were also involved in presentations of findings and in discussions about next steps and recommendations for oral health commissioners and local stakeholders.

Healthwatch Bucks collected data over two phases. The first involved families of children with and without additional needs. This generated important insights about the needs of SEND children, therefore they repeated the activity with only parents and caregivers of children with additional needs. In addition to Community Connector interviews, Healthwatch Oxfordshire supplemented the work by extending it to an online survey open to parents and caregivers of children with additional needs from all areas of Oxfordshire. It received responses from 38 people. They also visited a group of 10 asylum-seeking families in hotel accommodation to listen to their experiences around oral health and dental care. This additional insight is included here, although it is not funded under **Core20Plus5** programme (see **Appendix 3**).

3 Community participants

Table 1 below summarises the number of participants covered by interviews and survey in each of the three Healthwatch projects.

Table 1. Number of participants in each Healthwatch project

	Healthwatch Bucks	Healthwatch Oxfordshire	Healthwatch Reading	Total
Parents and caregivers	94	96	25	**215**
Under-10 children	111	113	47*	**271**
Total	**205**	**209**	**72**	**486**

*Note: four children included in Healthwatch Reading's analysis were aged 10 years old

The Healthwatch projects heard from a total of 215 parents and caregivers, relating to their experiences of supporting oral health care to 271 children.

Not every Healthwatch recorded comprehensive demographic information about their project participants (for more detail, see individual Healthwatch reports in **section 8**). Although most were women, collectively they covered a range of other characteristics including age group, religion, ethnicity, marital status, health conditions and disability, and whether they were a parent or caregiver for one or more children with additional needs. Most children had seen a dentist twice or more in the past year, although several had not seen one at all.

4 Main findings

This section brings together the main findings from the three Healthwatch projects. It highlights common themes and individual insights based on parents' and caregivers' accounts of their children's oral health, tooth brushing routines, attempts at keeping their children's teeth and gums healthy, and experiences of dental care.

While some findings only appeared in one or two reports, this does not mean that they were not present in the other project area(s). Gaps are likely to reflect the relatively small number of participants and limited opportunity for each project to explore parents' and caregivers' full range of experiences in depth.

4.1 Parents' and caregivers' views on children's oral health

Parents and caregivers in all three Healthwatch reports tried to ensure their children's oral health. Most said they were aware of the risks of poor brushing and of consuming too much sugary food and drink. Many were concerned about their children's teeth and gums as well as being able to access dental care when they needed it.

Parents and caregivers of children with additional needs experienced particular challenges and concerns. For example, more than half in the Healthwatch Bucks report said that they were either worried or very worried about their children's oral health.

4.2 What helps families support children's oral health?

Parents and caregivers were asked what they found most helpful and easiest when trying to keep their children's teeth and gums healthy. The three Healthwatch projects identified a range of methods parents and caregivers used to support their children's oral health.

For the analysis in this report, these were organised into three broad categories of support:

- **Behavioural support**
- **Practical support**
- **Professional support**

Table 2 below summarises the themes present in interviews and survey responses for each of the three Healthwatch projects.

Table 2. Factors that helped parents to support their children's oral health

	Bucks	Oxfordshire	Reading
Behavioural support			
Educational resources	✓	✓	✓
Positive routine	✓	✓	✓
Rewarding good oral health		✓	✓
Supportive supervision	✓	✓	✓
Practical support			
Special toothbrushes/toothpaste	✓	✓	✓
Using timers	✓	✓	✓
Brushing as a family	✓	✓	✓
Reducing sugar intake		✓	✓
Flexibility around brushing			✓
Professional support			
Advice from dentists and at school	✓	✓	✓
Healthy eating in schools		✓	

4.2.1 Behavioural support

Behavioural support involved efforts to encourage children to learn about good oral health and to properly brush their teeth and gums.

Educational resources

Families highlighted the need to educate and remind children about oral health. Parents and caregivers in all three areas said they used educational resources and media (videos, children's TV programmes, books, songs, apps) to teach their children about the importance of good oral health and the consequences of not properly brushing their teeth:

"We watch the Peppa Pig episode where they visit the dentist and we re-enact it / play it out." (Healthwatch Oxfordshire)

"It has been easy as I have used videos for him to learn how to do it and he enjoys it." (Healthwatch Bucks)

"I do go on internet sometimes. I recently just found out that when you brush, you're not supposed to rinse your mouth out. Yeah, I didn't know that." (Healthwatch Reading)

Parents and caregivers of children with additional needs also used singing and music or playing apps that made brushing teeth more fun.

Positive routine

Healthwatch Oxfordshire and Healthwatch Reading found that establishing and reinforcing a positive routine was important in facilitating good oral hygiene. This included having a consistent time and frequency of brushing, and using methods the child enjoyed. A consistent routine was especially important for encouraging children with additional needs to accept teeth brushing and help them learn:

"We have been able to manage looking after their teeth from a very early age. Their autism is mild. We helped them build a routine, let them know this is what you need to do – morning and evening before they go to bed. For the last two years they have been doing it by themselves. We encourage them." (Healthwatch Reading)

"I've always been quite of a health freak when it comes to brush their teeth and stuff like that. I implemented that as soon as they had one tooth, I had a toothbrush. Yeah. So I've always been on top of it so my children know it's routine. In the morning. If you're home after school, brush it after you've had a snack. Yeah. And before bed. So they need to get a routine." (Healthwatch Reading)

Rewarding good oral health

Other behavioural support for all children included using incentives such as stickers or praise to encourage them to practice good oral hygiene. Others said that routine and effective parenting helped, and some used sanctioning as an incentive:

"He is in a routine of brushing his teeth. He listens to me and if he doesn't brush, I tell him he will not get any sweets." (Healthwatch Bucks)

"I give them points so if they get up to 100 points, they can get a coin or maybe a chocolate coin. This helps to make them to it regularly. Or at least in the morning. My little one would come and copy it because he would see me do it in the morning." (Healthwatch Reading)

Supportive supervision

Most parents and caregivers said they were actively involved in their children's oral health, including supervising them while they brushed their teeth, checking their teeth and gums after brushing where possible, and some brushed their children's teeth for them when necessary. Families said watching their older siblings brush their teeth or brushing at the same time helped their children learn and encouraged them to do the same:

"All is easy because he has to watch siblings do it." (Healthwatch Bucks)

Children who enjoyed brushing their teeth were easier to support. Healthwatch Bucks noted that, even though most children benefited from supportive supervision, in some cases they did it on their own initiative:

"As my child is now 6 [years old] she understands and can brush her teeth herself." (Healthwatch Bucks)

4.2.2 Practical support

Practical support included providing materials or equipment that encouraged (or sometimes needed) children to practice good oral health. All Healthwatch heard from families of children with additional needs who used specially-designed toothbrushes and flavoured toothpaste:

"She likes flossing and she likes children's toothpaste. She has various kinds of toothbrushes to make it fun - electric, and 3 ways." (Healthwatch Bucks)

"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 3 sides). This means he doesn't need the toothbrush in there for so long, and so there is less chance of him getting distressed." (Healthwatch Oxfordshire)

"I put him in a certain position where his back is in me, and I hold his chin. So, he leans against me to he doesn't move so much. And we

stand over the sink. He likes it. He is used to it. He used to bite down on the toothbrush so you couldn't clean. But now we have the new position it works better." (Healthwatch Reading)

Some parents and caregivers also used gadgets or incorporated specific practices into their routine:

"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." (Healthwatch Oxfordshire)

"I put on a timer so they can watch that, they can see the time ticking down, so they know how long to brush…we also like to put a song on, the 'teeth' song - so they can kind of like, brush and have fun you know, you can get in a bit of a jig to it." (Healthwatch Reading)

The above examples indicate that parents and caregivers found it easier when their children enjoyed brushing or used fun or attractive gadgets, toothbrushes and toothpaste. However, methods did not always work and often meant experimenting with different routines, toothbrushes, and toothpastes, and adopting whichever worked best, using a "trial and error" approach:

"…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 error." (Healthwatch Oxfordshire)

4.2.3 Professional support

Community Connectors from Healthwatch Oxfordshire and Healthwatch Reading heard that parents and caregivers valued information and advice from dental practices and schools. Some families found information and guidance from health visitors helpful during the early childhood developmental stages.

"We got information from the health visitor at the one-year review when we were introducing the children to eating…Things like

brushing gums and stuff. They just gave me a bit of an idea…and it was helpful because then you start young and you can keep it up." (Healthwatch Reading)

Professional advice was informative and helped reinforce the importance of good oral health. Some families also said it was helpful when schools encouraged or facilitated healthy eating.

4.3 What challenges do parents and caregivers experience in supporting children's oral health?

Table 3 below summarises the range of challenges that parents and caregivers faced when trying to support their children's oral health.

Table 3. Challenges in supporting their children's oral health

	Bucks	Oxfordshire	Reading
Awareness and education			
Knowledge/understanding*		✓	✓
Information and support			✓
Behaviour and practice			
Resistance/avoidance*	✓	✓	✓
Sensory issues*	✓	✓	✓
Limited dexterity*	✓	✓	
Family and caring context			
Family/personal circumstances		✓	✓
Managing sugar consumption	✓	✓	✓
Buying toothbrush/paste*	✓	✓	
Access to dental care			
Finding a dental service*	✓	✓	✓
Getting a dentist appointment	✓	✓	✓

Note: Rows marked with * refer to challenges that parents/caregivers of children with additional needs often found especially difficult to manage.

4.3.1 Awareness and education

Both Healthwatch Oxfordshire and Healthwatch Reading heard that a lack of knowledge and awareness of children's oral health contributed to problems. Some parents and caregivers said they had not learned about oral health themselves. Poor knowledge and uncertainty meant they didn't know how to take care of their children's teeth:

“I don’t want my children to [have problems with their teeth]. But I don’t know how to help them. Like when you asked me if I check their teeth after brushing. I don’t do that. Do I have to check them? The health visitor came when they were about 4 but they didn’t really have a conversation about teeth.” (Healthwatch Reading)

“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.” (Healthwatch Oxfordshire)

Some parents and caregivers felt that they did not have enough information about oral health care, especially for very young children. One person in the Healthwatch Bucks project said they did not know “how to access the dentist.” Healthwatch Reading noted ‘a gap in parents' knowledge’ about local help they are entitled to, such as access to a community dentist service as well as a lack of information and guidance on how to register with an NHS dentist.

4.3.2 Behaviour and practice

Parents and caregivers in all three Healthwatch reports talked about challenges in getting children to brush their teeth generally and at certain times of the day:

"I find it hard to get her to brush her teeth in the morning. Evening, brushing her teeth she finds better.” (Healthwatch Bucks)

“I find it difficult to brush my youngest child’s teeth but easier to brush my oldest child’s teeth because I can just tell her to brush her teeth and then just stand and watch. But for the youngest, he struggles a lot because he does not understand what I say or what I want him to do. In the evening it is especially difficult to make them brush their teeth. When they are playing or sleepy it is difficult to get them to do it.” (Healthwatch Reading)

Healthwatch Reading reported the main reasons why children resisted brushing their teeth as ‘stubbornness, dislike of the toothbrushing process, or distractions from other activities such as watching TV’.

Children with learning difficulties or additional needs were more likely to experience particular difficulties. Healthwatch Oxfordshire and Reading heard that it was difficult to support children with additional needs such as learning difficulties who didn’t understand the need to brush their teeth:

"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." (Healthwatch Oxfordshire)

"There is a lot, as a special needs child, that he cannot do. I will probably brush his teeth for at least another 5 years. He is not capable of doing it himself. He doesn't have the mental capacity to understand how to clean his teeth." (Healthwatch Reading)

Children with certain developmental disorders (e.g. autism) might react with strong resistance to the daily 'demand' of brushing their teeth. Some with sensory conditions also found brushing painful or distressing because they disliked having their face or mouth touched. Others would often bite or chew the toothbrush:

"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." (Healthwatch Oxfordshire)

"He is diagnosed with autism spectrum disorder (ASD) and starts playing up when its teeth time. I have tried different toothbrushes and pastes, but it is still hard. [He] often bites the toothbrush or doesn't actually brush." (Healthwatch Bucks)

"My 5-year-old is non-verbal with ASD and an eating disorder called Pica. It affects them badly to the point where my son will self-harm. If we are going through one of those meltdowns in the evening, it is hard to get him to do things like brush his teeth." (Healthwatch Reading).

Therefore, besides a general resistance to brushing teeth, parents and caregivers of children with additional needs experienced significant challenges to practicing adequate oral health care. In all three Healthwatch projects, families of children with additional needs described challenges with their children 'getting upset and having tantrums' or having 'struggles with meltdowns':

"…my oldest because she has like, issues around and like meltdowns and things like that. If we are going through one of those in the evening it is hard to get her to do things like brush her teeth. When she has calmed down a little it's a little easier. But when she's really heightened, especially because that is a sensory issue too having a toothbrush put in your mouth when you are in the middle of a meltdown, it can be quite a lot." (Healthwatch Reading)

For these parents and caregivers, it can be a "daily battle" that might lead them to physically restrain their child to be able to brush their teeth. One person said that all their attempts at brushing had failed and that their dentist had advised them to focus on managing their children's oral health through diet, therapy, and reducing grinding their teeth.

Other challenges included children with additional needs who could not remember whether or not they had brushed their teeth, had poor coordination or dexterity, were inconsistent with brushing, or had difficulty concentrating for the recommended two minutes. These challenges meant that children with sensory or other additional needs might not practice adequate brushing or found it stressful to go to the dentist. It also made it difficult to carry out dental examinations and treatment:

"Four teeth were not good and because he is autistic it was difficult [for him] to sit down all the time. My child didn't like the dentist, so they referred him to hospital because of concerns." (Healthwatch Bucks)

4.3.3 Family and caring context

Parents and caregivers described how aspects of their personal and family circumstances affected their ability to look after their children's oral health and dental care. These included moving to a new area, having a challenging household situation, time constraints, parental separation, and pregnancy. One parent in the Healthwatch Reading project reported having difficulty ensuring a consistent oral hygiene routine when her son visited family relatives:

"Although I'd stopped giving him treats in my home, when he was going to his grandparents or Dad's they didn't really grasp the concept or the importance of it and he used to get his own way

whenever he used to go to them. Then I have to bear the consequences of that, and this has been difficult."

All three reports showed that caring for children's oral health required time and effort, especially for children with sensory or learning difficulties. Parents and caregivers in Healthwatch Oxfordshire and Healthwatch Reading projects said they sometimes lacked the time or energy to ensure that their children ate properly or to check that their teeth and gums were clean:

"Sometimes I have an early or late shift start and they can skip it if their sister is not watching them brush their teeth." (Healthwatch Oxfordshire)

"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 - 1 hour. It can be draining, especially when I 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." (Healthwatch Oxfordshire)

"Sometimes I check her teeth when I have time. In the morning, we usually don't have time, so I don't check, but yesterday was the weekend so I checked her teeth and I brushed her teeth." (Healthwatch Reading)

Healthwatch Oxfordshire heard from one caregiver who, due to homeschooling their child, had little access to support from school health advisors and a co-parenting father with a son with additional needs who said that moving between parents disrupted the routine that was necessary for the child to agree to brush his teeth:

"With his teeth, he has to brush them before he goes to bed and when he 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." (Healthwatch Oxfordshire)

Parents and caregivers said they sometimes found it difficult to ensure their children had a healthy diet or manage their sugar consumption. This was because they could not supervise what they ate or because didn't like to deny them sweets:

"It is difficult for me not to give him sweets because he likes them a lot and it has been the cause of a cavity he had." (Healthwatch Bucks)

"Difficulty when it comes to looking after teeth, I think I would say sugary foods like controlling the sugar, like sweet stuff, controlling that. How much they eat in a day. Especially for young ones, like my daughter, she understands. But for my son, if you have had too much sweets today, no more candy for you today. He will not understand. I think that is the hardest part." Healthwatch Reading)

"I do worry how many sweets and coke she buys on the way to school." (Healthwatch Oxfordshire)

Healthwatch Oxfordshire found that some children with sensory difficulties might have dietary issues which resulted in them refusing to drink water or milk from a bottle. Healthwatch Bucks noted that some parents and caregivers found it hard to choose an adequate toothbrush. Some parents and caregivers talked about the higher costs of buying special toothbrushes and toothpaste:

"So, like a toothbrush will be £5.99 at least. And autistic children like you know, they would damage their toothbrush within 5 minutes. And then again, I have to go for a new one, again I have to go for a new one." (Healthwatch Oxfordshire)

The high cost of living meant that many families had to prioritise other household expenses above oral health. One Healthwatch Oxfordshire caregiver said they could not meet all their children's oral health needs:

"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." (Healthwatch Oxfordshire)

Although some people were able to claim certain oral health care costs through the benefits system, some toothpastes they used to receive on prescription where no longer provided for free.

Healthwatch Oxfordshire also spoke to some asylum-seeking families living in hotel accommodation. Their status and circumstances presented them with several challenges regarding both child and adult oral health, from inadequate understanding and information, language barriers, and access to dentists. These are described in **Appendix 3**.

4.4 Access to dental practices and appointments

Most parents and caregivers in Healthwatch Bucks' and Healthwatch Reading's projects said they had registered their child or children with a dentist and most children had visited a dental practice twice or more in the past year. However, some children were not registered and several had not recently been seen by a dentist.

Access to dental services was a prevalent theme in all three Healthwatch reports. Parents and caregivers of children with and without additional needs shared their experiences of looking for a suitable dental practice and booking appointments for routine checkups and treatment.

4.4.1 Finding a local dentist and registering children

Families in all three Healthwatch projects said it was difficult to find a local NHS dentist who would register their child or give them dental treatment:[17]

"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." (Healthwatch Oxfordshire)

[17] Healthwatch Oxfordshire has carried out 'mystery shopper' work, anonymously contacting local dental practices to find out whether they are taking on children and adults for NHS dental care. See https://healthwatchoxfordshire.co.uk/news/accessing-nhs-dentists-in-oxfordshire-april-2024-update/.
Healthwatch Bucks also undertook a similar (not anonymised) exercise through a telephone survey with local practices. See https://www.healthwatchbucks.co.uk/2024/04/experiences-of-accessing-a-dentist-as-a-new-patient-in-buckinghamshire/

"Neither me or my children are registered with the dentist and so they are missing out on 6-month visits. We tried lots of different dentists near us and they did not have space." (Healthwatch Reading)

Some people said they did not know where or how to locate a dental practice. While this was the not usually the case for regular dentists, it appeared that some people had no knowledge of the community dental service or found it difficult to find one:

"I have never seen a community dentist. I did not know that existed. I have never heard of it. I think they should tell us about these things at the school." (Healthwatch Reading)

While not universal, some parents and caregivers of children with additional needs said that their child's disability had made it more difficult to find suitable dental care. Their main concern was whether the dental service would be able to accommodate their child's particular individual needs.

4.4.2 Dental appointments

The three Healthwatch projects described mixed experiences of getting dental appointments. Some parents and caregivers in Healthwatch Bucks and Healthwatch Reading appreciated getting regular routine appointments. receiving appointment reminders:

"I have been lucky to find friendly dentist for my family. I get reminders and messages…for my family checkups. This helps me keep on top of it." (Healthwatch Bucks)

"Very positive. We moved to High Wycombe five years ago and I don't have any problem with appointments, [they are] every 6 months." (Healthwatch Bucks)

"I've had a quite good experience to be fair, I haven't had to wait. They send me a reminder and I just book in online and we just go straight ahead. I can contact them as and when I need to. The last time that we went was the end of last year and he had a good report – seems quite consistent now." (Healthwatch Reading)

All three Healthwatch projects heard about various challenges relating to dental appointments, including a general lack of availability, long waiting lists, cancelled appointments, emergency-only appointments, and inflexible timings.

Parents and caregivers said they often found that their local dental practices were not accepting new patients:

"Difficult...had to register in a town 30 minutes away as there are no local NHS ones." (Healthwatch Bucks)

"I could not register my child to a dentist anywhere because they were fully booked. I kept looking for a dentist then eventually found a dentist which would register her at the age of 6." (Healthwatch Bucks)

Sometimes I find it hard because they don't have appointments straight away. So sometimes there is six months wait unless it is an emergency and even within emergency, it's not sure they can give me an appointment. That's one hassle I have with accessing the dentist. (Healthwatch Reading)

Healthwatch Bucks and Healthwatch Reading noted that the COVID-19 pandemic had made it even more difficult:

"Tried to find an NHS dentist. Was very hard after Covid, but the dentist I got in the last 18 months is good. Contacting the dentist is hard." (Healthwatch Bucks)

"Before covid I registered my daughter to the dentist and then she used to go twice a year, like every six months. But after lock down, I don't know - I couldn't access it. They said she is no longer registered at the dentist, she is no longer on the list. So I have been trying. Every time I call they say they are only taking emergency cases." (Healthwatch Reading)

For some parents and caregivers of children with additional needs, making the most of each appointment was important to avoid the need to postpone treatment and make repeated appointments, which wasted resources and delayed care:

"Finding appointments after COVID-19 has been very difficult. One month ago, he had his first check-up appointment after waiting several months and due to his disability, he did not open his mouth so they rescheduled another appointment in two months." (Healthwatch Bucks)

Parents and caregivers in across the three Healthwatch areas had experienced cancelled appointments:

"Our dentist cancelled their appointments and then they said the next available slots were 7 months away." (Healthwatch Oxfordshire)

"Have registered…booked an appointment and then the dentist cancels last minute." (Healthwatch Bucks)

"You know all the cancelling - just someone who cares as much as we care about our kids' teeth. You know like – with them keep cancelling. Like it's half term week – I cannot afford to take [time] off work [or my son] off school – he is in his last year, he is in year six. And they keep cancelling his dentist appointment…the dentist has just thrown me now because this February half term, he's got no dentist appointment." (Healthwatch Reading)

In some cases, dental practices were reported as only offering emergency appointments:

"It has been very difficult. We have been living here for 5 years and the NHS has never given me an appointment. When I call to ask for a check-up for my child, they tell me that if it is not an emergency, they will call me when they have space and [they] have never called me back. I have been taking my children to a private dentist out of this country." (Healthwatch Bucks)

Parents who were unable to get a timely appointment had to wait or, in at least one case, felt it necessary to pay for private dental care. Some parents and caregivers of children with additional needs were concerned about the possible consequences of cancelled appointments or ones that did not go well. One

Healthwatch parent worried that rebooking would mean waiting a long time or that their child might be deregistered from the dental practice.

Parents and whose first language was not English could always understand oral health information or advice and explanations given by health professionals. This made it difficult for them to apply appropriate knowledge and practice to support their children's oral health:

"My child has Hydrocephalus condition and Kalpana condition of the eyes. The difficulties I face are to understand the condition. Because of the language I need an interpreter or family member to translate when I go to hospital for appointments or the GP/dentist. I can't speak English and struggle understanding professionals." (Healthwatch Bucks)

4.5 Experience of visiting the dentist

Community Connectors from Healthwatch Oxfordshire and Healthwatch Bucks, reported that people were generally positive about their children's visits to the dentist. Positive experiences included dental staff giving useful advice, clear explanations, and having a child-friendly approach:

"The dentist was very clear and showed us how to brush my child's teeth. It was helpful the dentist informed [us] in front of my child which helped to keep his oral hygiene." (Healthwatch Bucks)

"Our dentist is very good with children. They give stickers, it was overall a good experience." (Healthwatch Bucks)

The experiences of some parents and caregivers in Healthwatch Reading were more mixed:

"The dentist is good, but I think he just needs a little bit more time – to be a little bit more patient with the kids. Because I am coming from another country, I am just comparing between my country where I lived before, and we had a specific dentist who was working with the children. So, when you see the kids in the chair with the light going up – they start to be scared. I know that if she's working with the time and she has only 10 minutes for the patient, but they are

kids...they need more time when they work with the children." (Healthwatch Reading)

Healthwatch Oxfordshire found that parents and caregivers had positive experiences when dental care staff were patient with their children and took the time to make them feel comfortable. This sometimes involved attending some 'practice' appointments as a simple introduction for the child to visit the dentist, get used to dental instruments, and allow the dentist to check their mouth:

"What makes it easier is the support that I've been given from the children's dentist and the specialist dental nurse...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." (Healthwatch Oxfordshire)

Healthwatch Oxfordshire reported that, while some parents and caregivers experienced these facilities at regular NHS dentists, they appeared to be a more prominent feature of specialist community dental practices. Healthwatch Bucks and Healthwatch Reading also found that parents and caregivers of children with additional needs valued specialist community dental practices where staff understood neurodiversity, accommodated children's conditions, and provided supportive care:

"The understanding of neurodiversity is a very positive point in our dentist, which helps a lot." (Healthwatch Bucks)

"The dentist was excellent. I informed them in advance about my child's condition, and they accommodated to [their] needs." (Healthwatch Bucks)

"It has actually been quite good. Before he was agitated but now he actually sits in the chair. The experience has got better for him. The approach and environment at the community dentist is different from an everyday dentist." (Healthwatch Reading)

All three Healthwatch heard from families with children who had had teeth extracted. As above, parents and caregivers valued the opportunity to have introductory appointments and appreciated dental staff who explained processes and procedures. Involving children in checkups and treatment, and reassuring them was also helpful. One parent recounted their experience of taking their two children to a specialist community dentist for tooth extractions:

"...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...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." (Healthwatch Oxfordshire)

However, Healthwatch Reading reported mixed experiences of tooth extraction:

"...she had her tooth taken out and they did say, because it was cracked straight across the middle, it was quite hard to take all of it out, and it might be difficult to take all the tooth out so there might be a little bit left in. So, for a little while she was left with a lot of pain. And actually a week later, once it all settled down, there was a little bit left in. And a good couple of weeks later she was still in pain. Then they had to refer her to the hospital so she could get the rest removed. So, I feel like she's had a bit of a bad experience with the whole tooth taken out." (Healthwatch Reading)

Although there were several examples of positive experiences of dental care, other parents and caregivers in Healthwatch Bucks' and Oxfordshire's projects felt that their dental practice did not show enough consideration for the challenges they faced or did not make adjustments for their children's needs:

"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." (Healthwatch Oxfordshire)

“No adjustments made at NHS dentist so equipment, jargon used and understanding of neurodiversity lacked. They are frightened to go back.” (Healthwatch Oxfordshire)

Similarly, parents and caregivers had poor experiences when dental staff did not have a child-friendly approach:

“The dentist who checked him was not very kind or patient…there was no empathy so that is why the appointment was rescheduled.” (Healthwatch Bucks)

“The experience for my son is very unpleasant every time we go to the dentist because he gets very scared and screams sometimes and the dentist, despite being patient, also gets stressed.” (Healthwatch Bucks)

Staff changes in some dental practices meant that children could not benefit from continuity of care and had to adapt to new conditions each visit. Appointment times that clashed with school times and insufficient appointment duration to allow children to feel comfortable having their teeth and gums examined created problems:

The times- because if it is during school time, you’d like it to be in the morning or after school. That means the child is having time off school to go to the dentist. It’s travelling to the dentist and then taking them back to school. And if they have had a filling or something then they don’t want to go back to school. It is getting it at the right sort of time. You would think they would have reserve appointments for children so they could come first thing in the morning.“ (Healthwatch Reading)

The dental practice environment also influenced families’ experiences of dental care. Parents and caregivers commented that waiting for treatment to start can distress children with additional needs. For example, pictures of clinical equipment or images of oral health diseases easily triggers their anxiety or fear. Healthwatch Oxfordshire included an example involving an autistic child who became very distressed while waiting for a tooth extraction because the appointment was delayed. One parent said they felt judged by hospital staff when their child was too frightened to let them administer anaesthetic.

4.6 Sources of information and support

Parents and caregivers said they sought or received information and advice about children's oral health from a variety of sources, including:

- Child's dentist
- Friends and family
- Other parents
- Support group
- Child's school
- Own experiences
- Internet (Google search, social media, e.g. TikTok)
- Health visitor
- Social worker
- Television

Parents and caregivers used various sources for different types of information (e.g. dental hygiene products, advice for oral health problems). Most obtained advice and information from more than one source, depending on what they wanted to know and what was available:

"…we got some bits from school when they got some information and did the topic at school all about the teeth and stuff. And then just a bit off everywhere. You just grab a bit off the internet, the telly, new toothpastes. Things like that." (Healthwatch Reading)

The most common source of information and advice in Healthwatch Oxfordshire and Healthwatch Bucks was the child's dentist. Parents and caregivers valued their expertise and trusted their advice. Some said that it helped them give guidance and instructions to their children.

"Asked dentist to explain nighttime cleaning importance at last check up. Dentist gave son a leaflet explaining importance." (Healthwatch Oxfordshire)

Healthwatch Reading reported parent's own experiences as the most common source of information. They relied on their own knowledge and abilities, and the

effectiveness of their methods, which were often passed down through generations or learned through trial and error:

"My own experiences because my parents emphasised on brushing teeth as a child." (Healthwatch Reading)

"I just knew what to do like starting to use my fingers with tooth paste to start with and just carried on." (Healthwatch Reading)

Friends and family were also asked for advice because they were trusted and dependable. Parents and caregivers of children with additional needs often asked friends and other people with similar children because of their knowledge and lived experience:

"The most useful advice has come from autistic adults - they have the lived experience." (Healthwatch Oxfordshire)

"I was told from another family friend with a special needs child." (Healthwatch Reading)

Health visitors were viewed as important sources of information because they visited new mothers and had the opportunity to advise on oral health while the child was still young. However, feedback about the quantity and consistency of information was mixed. While parents who did receive advice and guidance valued it, some said they had not received any information about oral health during their visits:

"When we had the 2-year check from the health visitor, teeth weren't even mentioned. Height, weight but not teeth…it's almost seen like it's a separate thing, but teeth are very much intwined with health. It would be useful because you see them a lot when your children are young." (Healthwatch Reading)

Most parents and caregivers in Healthwatch Oxfordshire's project said they found the information they received helpful and understandable. However, those with children with additional needs said that information was often too generic and unhelpful for their family situation or child's needs:

“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.” (Healthwatch Oxfordshire)

Internet searches, social media, and television were considered convenient and useful resources to find things out quickly. Almost half of families in the Healthwatch Reading project used these sources. However, some parents and caregivers said that they treated the information from these sources with caution.

4.7 What would help improve children’s oral health?

Parents and caregivers were asked what might improve support for children’s oral health. Note that they are not our formal recommendations but comments that were captured in the Healthwatch project reports. The suggestions are presented in **Figure 2** according to categories of intervention.

Figure 2. Parents’ and caregivers’ suggestions to improve children's oral health

Category	Suggestions
Education and information (including SEND-specific)	• Dental advice (e.g. dental hygiene) • Food and diet • Special toothbrushes & toothpaste
Oral health promotion	• Healthier food system • Oral health activities in schools • Brushing teeth at school
Dentists and appointments	• More NHS dentists • More appointments/shorter waiting lists • Flexible timings/longer appointments
SEND-friendly approach	• Training on neurodiversity • Greater awareness of SEND children’s needs • Adaptable appointments, calming waiting rooms
Integrated services	• More collaborative working between health and non-health professionals (GPs, health visitors, SEND practitioners)
Language support	• Plain, non-technical language • Information and advice in different languages • Better access to interpreter services

5 Reflecting on the Community Connector model

Each Healthwatch project used a similar approach to identify, recruit, and train Community Connectors. Overall, Healthwatch staff reported very positive experiences of using the model and received encouraging feedback from Community Connectors. Project staff also gained valuable learnings about how successfully implement future Community Connector projects.

Major strengths of the model included:

- Harnessing Community Connectors' motivation to help people in their communities:

"I love being a community connector because my main motivation is to help the community and make their lives better." (Healthwatch Bucks)

- Facilitating the building of positive relationships with people in the community:

"The project was amazing opportunity for us Community Connectors to connect with people in our community and build up a good relationship with them." (Healthwatch Reading)

- Capitalising on the ability of Community Connectors to engage with people who would otherwise be unlikely to openly discuss personal or sensitive topics. Community members often felt a degree of "shame and mistrust around health issues" and feared disclosing their lack of knowledge or difficulty ensuring adequate oral health for their children:

"My son is autistic and hates brushing his teeth and going to the dentist, and I know a lot of friends whose children have issues with their teeth. I think that often with things like this, people don't always want to speak out about the problems they're having. They worry they might get into trouble or be judged." (Healthwatch Oxfordshire)

"It has helped our community address important issues which they will not share with an outsider" (Healthwatch Bucks)

- Creating a 'safe space' for more open conversation because the Community Connectors were from the same community and had shared lived experiences.
- Facilitating the collection of a large number of stories and experiences through their presence and connections in the community.
- Empowering for Community Connectors and the community
    - It built on the skills and interests of Community Connectors and their willingness to help their local community.
    - Its inclusive approach enabled community members to be heard and to share their concerns and experiences.

'Parents/carers felt empowered to take control of their own and their families' oral hygiene and overall dental care having gained more health knowledge and awareness during the interviews.' (Healthwatch Reading)

- Increasing awareness and providing communities with important information about children's oral health, available local dental services (including community dental practices) and how to access them:

"There needs to be a lot of awareness among communities in marginalised areas, among minoritised communities about issues such as accessing dentists and other areas that cause health inequalities." (Healthwatch Reading)

"Some parents did not know they don't have to pay for NHS services such as GPs and Dentists." (Healthwatch Reading)

- Raising awareness of Healthwatch and, therefore, other relevant local charities and organisations.

Staff experienced a number of challenges to implementing their projects. These included:

- **Timeframe**

It is crucial to allocate sufficient time to each project phase. Recruitment required considerable effort, involving visiting local organisations such as schools and community centres, speaking to as many people as possible, and 'marketing' the project to encourage people to take part. Community Connectors need time to reach out to communities and to build on their existing relationships. They also

require considerable support to carry out their role effectively. Some staff felt that the time allocated for the project was short and made difficult by taking place over winter.

- **Access to families**

Healthwatch Reading noted that cultural ethnic differences between non-white Community Connectors and some community members presented a significant challenge. Some families were reluctant to engage with them:

"There was a lack of trust about who we were even though we had ID badges. This lost us valuable time." (Healthwatch Reading)

They also experienced language difficulties, for example when translating during in-depth interviews and transcribing recordings

- **Logistical considerations (mostly reported by Healthwatch Reading)**
    - Equipment and materials required by Community Connectors (e.g. audio recorders, Healthwatch ID and T-shirts).
    - Families not keeping appointments for interviews.
    - Finding suitable locations for interviews, e.g. a quiet environment and where people feel safe and comfortable to talk.
- **Ongoing support for Community Connectors**
    - How to support Community Connectors after the completion of the project.[18]

Suggestions for maximising the effectiveness of the Community Connectors model in similar settings included:

- Planning community engagement activities to raise awareness about our work and health and social care issues.
- Developing working relationships with community organisations and collaborating on activities.
- Developing and providing clear guidelines about the project prior to recruiting Community Connectors, including:
    - What is aim of the Community Connector approach?
    - What is their role and how to implement it?
    - How will Community connectors be trained?
    - What renumeration will be offered?

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[18] Healthwatch Oxfordshire have experienced some of these challenges in their work with community researchers. See: https://healthwatchoxfordshire.co.uk/our-work/community-research/

- Sound preparation before Community Connectors engage with local people, including:
    - Are they clear on what they are expected to do?
    - Do they understand the subject area (e.g. children's oral health)?
    - Have protocols been established for monitoring and supporting Community Connectors in the field?
    - Do Community Connectors know how to ask for support and report back?
- Compiling a list of Community Connectors for them to contact each other for information and support.

6 Summary of main findings

This report explored the main findings of three Healthwatch oral health projects, each of which is available through the links in section 8 below. The findings indicate that most parents and caregivers try to support their children's oral health through routine hygiene practices and regular dental care. Although families might be aware of the links between oral hygiene, poor diet, and tooth decay, some are constrained by poor socioeconomic conditions and the current high cost of living, making it difficult for them to provide the best for their children such as high quality, healthy food.

The findings presented in this report highlight the need for parents and caregivers to have an understanding of children's oral health issues and good brushing practice. For this they require information and guidance, especially for children with additional needs, such as brushing techniques to use at home, suitable toothbrushes and toothpastes for children. Oral health practitioners, allied professionals, schools, and other organisations are all important sources of relevant and credible information.

Some families in the Healthwatch projects experienced challenging social and financial circumstances (e.g. insecure housing, parental separation, and asylum seekers). These wider social determinants influenced their ability to support their children's oral health. Parents and caregivers of children with developmental disorders or other additional needs also face challenges; they often have to take special measures to ensure their children's teeth are adequately brushed and treated without causing them excessive distress. All of these families can experience difficulties accessing a suitable dental health service that meets their children's needs. Ensuring implementation of the Flexible Commissioning Scheme can improve access for people like these who have not recently been able to access a dental consultation or are new to the area.

Parents and caregivers need be able to access timely and appropriate dental services to meet their children's oral health care needs. At present, a lack of capacity for dental practices to accept new patients and low availability of appointments are major obstacles. Children with additional needs are well served by specialist community dental practices because staff have the necessary resources and skills to address their individual needs. However, not all families are aware that these services are available or how to access them. Other dental practices also provide exemplary care which can be harnessed to share with others.

This report summarises findings from interviews and survey data from a selection of parents and caregivers from specific communities in the three study areas. The findings do not necessarily reflect the experiences of other parents or caregivers living in other communities or areas. However, it offers insights into some of the main considerations and challenges that parents and caregivers of young children experience when trying to ensure their oral health.

7 Recommendations

This report contains two sets of recommendations. Those listed below are intended for BOB ICB in the planning and provision of publicly-funded dental services across Buckinghamshire, Oxfordshire and Berkshire West. In addition, each Healthwatch report has identified a set of locally-specific recommendations, which can be found in **Appendix 1**.

This report will be presented to BOB ICB Prevention and Health Inequalities Committee for discussion and action.

Recommendations for BOB ICB

1. Inform and encourage local place-based stakeholders to review individual Healthwatch reports, taking special note of the findings and recommendations for each area (see **Appendix 1**).
2. Review and promote initiatives in educational settings of all levels to ensure that children learn about oral health and practice good dental hygiene (e.g. provision of educational resources and supervised brushing).
3. Continue efforts at reducing oral health inequalities including:
   - Enhancing existing BOB ICB strategies – such as **Start well** – that support families and communities to ensure their children achieve good oral health.
   - Commissioning or supporting community oral health improvement interventions in deprived communities that raise awareness of oral

hygiene and help parents and caregivers make informed choices about their children's oral health.[19]

- Continuing to support and raise awareness of the Flexible Commissioning Scheme to improve access to oral health care for groups who have been unable see a dental practitioner or have recently moved to the area.
- Further developing initiatives such as the Community Connector model as a valuable means of engaging with communities and hearing about local people's experiences of oral health, as well as building trust and increasing reach.
- Linking with organisations that work with communities experiencing health inequalities to better understand their needs and experiences, and as an opportunity to increase awareness of oral health and local dental services.
- Ensure the provision of accessible interpreting services and translated written materials for families whose first language is not English.

4. In line with the BOB ICP **Integrated Care Strategy** of supporting children and young people with additional needs, emphasise the adoption of SEND-focused approaches to oral health. For example:
   - Explore ways to provide accessible, tailored information, advice, and support to more parents and caregivers of children with additional needs, including how and where to access to community dental practices.
   - Expand tailored, culturally sensitive training for dental and allied professions on the needs of SEND children, including involving people with lived experience to support the process. Training should adhere to the Oliver McGowan Mandatory Training on Learning Disability and Autism[20]
   - Promote activities and events for oral health professionals (perhaps considering involving other health professionals with knowledge and experience) based on shared learning and skills building. Examples might include seminars or 'lunch and learn' sessions.
   - Link and collaborate with local groups and organisations that support children with additional needs.

[19] See for example: https://www.nice.org.uk/sharedlearning/feeding-your-baby-sessions-to-deliver-oral-health-messages#key-learning-points

[20] https://www.hee.nhs.uk/our-work/learning-disability/current-projects/oliver-mcgowan-mandatory-training-learning-disability-autism

- Encourage greater engagement between parents/caregivers and local dental services with a view to increasing understanding of the barriers and facilitators to children's oral health, building relationships between families and practice staff, and facilitating a partnership approach to oral health provision.[21]

5. Using a multidisciplinary approach, continue a policy of sharing and building on current good practice, especially regarding the provision of SEND-friendly services, involving dental staff, health visitors, and other health professions.

6. Improve referral pathways to community dental services, including:
   - Providing clear information to parents and caregivers about available services, how to be referred, and self-referral.
   - Reviewing referral waiting times between dental practices and community dental services.

[21] Ideas from the Patient Participation Group (PPG) model at GP practices might be explored. See: https://napp.org.uk/for-patients/

8 Links to the individual Healthwatch reports

Please refer to the webpages listed below for links to individual Healthwatch reports

Healthwatch Bucks

https://www.healthwatchbucks.co.uk/category/results/

Healthwatch Oxfordshire

https://healthwatchoxfordshire.co.uk/our-work/research-reports/

Healthwatch Reading

https://www.healthwatchreading.co.uk/newsandreports

Appendix 1: Recommendations from individual Healthwatch reports

8.1.1.1.1 Healthwatch Bucks (initial report)

Early intervention

☑ Almost 9 out of 10 hospital tooth extractions among children aged 0 to 5 years are due to preventable tooth decay and tooth extraction is still the most common hospital procedure in 6- to 10-year-olds, according to Public Health England data up to 2019. Early years oral health promotion should be targeted at nurseries, pre-schools and local family centres.

☑ Recruiting Oral Health Educators or Community Oral Health Champions to raise awareness about by doing outreach in children's settings. As well as offering advice for maintaining good oral health, they could offer advice on balanced diets and healthy snacking

Dental visits

☑ Ensuring that NHS dentists in Buckinghamshire have up-to-date criteria and availability on the NHS Find a Dentist website https://www.nhs.uk/service-search/find-a-dentist

☑ Encouraging dental practices to reduce waiting times for appointments and rebook cancellations within a timely manner

☑ Encouraging parents and caregivers of children with suspected or diagnosed special educational needs when booking appointments to request that their dentist makes reasonable adjustments such as providing ear defenders, using child's very toothpaste flavour and other sensory considerations

Treatments and referrals

☑ Ensuring that dentists give enough time to treatment time appointments so that they are not rushed to manage the child's urgent care needs

☑ Reducing waiting times for NHS treatments by looking at ways to speed referral paths between dental practices and community dental services

8.1.1.1.2 Healthwatch Bucks (report on children with additional needs)

- Supporting early years and school settings to promote good oral health by having sugar-free policies for snacks and lunches. Also, supporting these settings to deliver a supervised toothbrushing programme
- Developing community-based multidisciplinary teams to promote oral health such as health visitors, speech and language therapists, special educational needs coordinators (SENCOs) and community pharmacies
- Promoting NHS clinical standards documents to parents/carers such as dental pain communication charts and dental passports as well as videos on how to complete a mouth check https://www.england.nhs.uk/publication/clinical-standard-oral-healthcare-for-autistic-children-and-young-people-and-or-those-with-a-learning-disability/
- Sharing NHS clinical standards resources for making reasonable adjustments in dentistry with all dental practices in Buckinghamshire https://www.england.nhs.uk/publication/clinical-standard-oral-healthcare-for-autistic-children-and-young-people-and-or-those-with-a-learning-disability/
- Advising dental practices to give more information to parents/carers about different flavoured or non-flavoured toothpastes, aids for brushing, grinding preventions and tips for looking after sore mouths. Also, encouraging them to provide this information in other more frequently spoken languages
- Looking at ways to speed referral pathways between dental practices and community dental services to avoid long waits which can cause more discomfort and anxiety for children who need urgent treatment

8.1.1.1.3 Healthwatch Oxfordshire

Recommendations for BOB ICB

- 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

Recommendations for Oxfordshire-based Place stakeholders (note: written responses from stakeholders will be published on Healthwatch Oxfordshire's website alongside the Healthwatch Oxfordshire report

These include 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 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 Community Dental Service CIC to ensure a joined up approach.
- For Thames Valley Community Dental Service – Oxfordshire (Oxford Health NHS Foundation Trust), and Oxford University Hospitals NHS Trust and others to work to improve waiting times, to 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 and others, 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

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8.1.1.1.4 Healthwatch Reading

- Implement community-based oral health education programmes to raise awareness about oral hygiene practices and good oral health. These could involve local healthcare providers, educators, and community organisations to broaden the programmes' reach.

For example, review the success of Anyone Can Cook! Feeding Your Baby sessions that took place in Wiltshire in November 2022 and consider running something similar within the top 3 deprived wards of Reading, with a view to potentially expand across Reading in the future.

"The ABC Cook mission is to encourage families and children to make healthy choices by developing a passion for cooking, infusing memories of food and food preparation that are both positive and fun. The Feeding Your Baby Sessions aim to demonstrate how quick, simple and fun weaning and cooking and eating together as a family can be. Promotion of good oral health, primarily in young children, but within families to reduce the number of children suffering from dental decay and requiring extractions under general anaesthetics."

(https://www.nice.org.uk/sharedlearning/feeding-your-baby-sessions-to-deliver-oral-health-messages#key-learning-points)

- Initiatives directly involving education settings and collaborating with them to integrate oral health education into the curriculum/learning.

The Early years foundation stage (EYFS) statutory framework, states that early years providers must promote good oral health of children who attend their settings; we suggest reviewing what schools, pre-schools and nursery settings are currently doing to promote good oral health, and if that can be improved upon – screenings, workshops and resources for children and parents etc.

Consider implementing an oral health initiative in Reading similar to Scotland's Child Smile and Wales' Designed to Smile. Both incorporate a targeted approach

by focusing on pre-schools, nurseries, and schools in the 3 most deprived areas of each country. The programmes they have created include:

- supervised tooth brushing in school or nursery/pre-school for 3-5 years old
- oral health promotion for key groups of children and their parents, and teaching professionals.
- promoting oral health from birth (0-3 years)

- Access to dental services that offer quality dental care for children and young people; create child-friendly dental environments to alleviate fears and make dental visits more enjoyable (timers, music, interactive resources to make oral hygiene fun and engaging), offer subsidies for regular check-ups, allow longer appointment slots so parents/carers can ask questions and receive oral health advice and resources for the home, and organise dental health fairs.

- Greater awareness and accessibility for families with children with additional needs to attend Thames Valley Community Dental Service. For example, parents/carers of children and young people on Reading Borough Council's SEND register could be directly informed and given information about the community dentistry service, and advice on tailored strategies to help with oral health at home, i.e. using different style toothbrushes and toothpastes for children with sensory needs etc. This will ensure parents/carers are aware of this service and given guidance as soon as possible given the extremely difficult challenges many families can face at home and at high street dental practices with children who have additional needs.

- Specialist training for dental professionals, including reception staff, at high street dental practices, to understand the needs of children with additional needs, and the specific challenges these children and their families face with oral health and hygiene.

  We suggest taking guidance from charities such as **The National Autism Society**, i.e. ensuring there are questions on dental medical questionnaires where parents/carers of children/young people with autism can ask for adjustments to be made to make their visit to the dentist a better experience. Children with additional needs to be booked into a double slot for their routine checkups etc.

- Creating culturally tailored resources such as developing culturally sensitive oral health resources and materials as different communities have differing needs, and to tailor any oral health programmes to their requirements.

- Cultural sensitivity is crucial for families from non-UK backgrounds who may be unfamiliar with the UK health system and other local support services. Language barriers can hinder communication and understanding, so offering interpreting services is essential for non-English speakers to express their oral health needs and to access dental care.

Appendix 2: Case studies from each of the three Healthwatch oral health projects

8.1.1.1.5 Healthwatch Bucks

Story 1. Overcoming Appointment Challenges and Promoting Oral Health Awareness

Background:

She encountered obstacles when trying to secure dental appointments for herself and her family. Additionally, her son experiences sensitivity in his teeth, leading to an interest in seeking advice on this matter.

Appointment Booking Challenges:

In her experience, securing an appointment at the dental clinic proved to be a complex task. Initially, she had to call and make appointments over the phone. However, if the clinic was fully booked for the day, they advised her to book online instead. The online option defaulted to private patient status, forcing her to repeat the booking process manually each day until she could secure an appointment as an NHS patient through phone booking.

Nighttime Routine and Sugar Awareness:

Our case study participant found establishing a nighttime routine challenging, particularly when her children were tired. However, she expressed that explaining the detrimental effects of sugar on their teeth was easier. Nevertheless, she expressed a desire for more advice regarding sensitive teeth, as her son experiences this condition.

By addressing these challenges and providing relevant support, we can enhance the accessibility of dental care and promote oral health awareness for this case study participant and her family.

Story 2. Establishing Oral Health Habits and Awareness in a Family Setting

Background:

Our case study focuses on a mother of four children, with the youngest child currently attending primary school. The mother has successfully established oral health habits and finds it easier to maintain those habits due to the influence of her older children. Regular dentist appointments are scheduled well in advance for checkups, ensuring proactive oral care for the entire family. Additionally, she holds the belief that fizzy drinks pose the greatest risk to teeth health.

Establishing Oral Health Habits:

The mother took proactive steps in teaching her children the importance of oral hygiene from an early age. Following the lead of her older siblings, the youngest child found it easier to adopt and maintain brushing habits. This successful implementation reflects the effectiveness of early education and parental guidance.

Proactive Dental Appointments:

Scheduling routine dentist appointments well in advance allows for regular checkups for the entire family. By being proactive in arranging these appointments, the mother ensures that any potential oral health issues can be detected and addressed promptly, contributing to the overall oral well-being of her children.

Awareness of Fizzy Drinks:

The mother recognises the detrimental effects of fizzy drinks on teeth health. Understanding the potential harm caused by excessive consumption of sugary beverages, she encourages her children to avoid or limit their intake.

By highlighting this successful case study, we can draw attention to the importance of establishing oral health habits from an early age, proactive scheduling of dental appointments, and promoting awareness of the dangers of sugary drinks. These efforts contribute to the overall well-being and dental health of the entire family.

Story 3. Challenges in Finding a Dentist and Concerns about Orthodontic Treatment

Background:

Our case study revolves around an individual who recently relocated to High Wycombe with their family. Encountering difficulties in finding a new dentist, they experienced a significant delay in obtaining an appointment. Additionally, they express concerns regarding future orthodontic treatment for their children.

Challenges in Finding a Dentist:

The individual and their family faced challenges in locating a suitable dentist in the new area. It was a time-consuming process that caused a delay in receiving necessary dental care. Finding a dentist who aligns with their preferences and requirements can be an overwhelming task during a relocation.

Appointment Availability:

Once a dental practice was eventually found, the individual discovered that the earliest available appointment was scheduled six weeks in the future. This prolonged waiting period highlights the limited availability of appointments, potentially hindering timely access to necessary dental services.

Orthodontic Treatment Concerns:

Expressing concerns about orthodontic treatment, the individual emphasises the importance of future dental needs for their children. Specific worries may relate to the availability of orthodontic specialists, the potential costs involved, and the overall effectiveness of treatment options.

In conclusion, this case study sheds light on the challenges faced when seeking a new dentist after relocating. Additionally, concerns regarding orthodontic treatment for the individual's children indicate a desire for access to suitable orthodontic care. It is crucial to consider these real-life experiences and concerns to improve accessibility to dental services and address anxieties surrounding orthodontic treatment for families in similar situations.

Story 4. Navigating Dental Care Options and Establishing Oral Health Routine

Background:

In this case study, we explore the experiences of an individual who moved to a new area. While they were successful in finding an NHS dentist for their daughter, they encountered challenges in locating one for themselves, leading them to opt for private dental care. Despite this, they established a consistent oral health routine for their daughter, utilising various tools and resources for an enjoyable brushing experience. Regular checkups are scheduled, thanks to proactive reminders from the dentist.

Dental Care Challenges:

Upon moving, the individual faced difficulty in finding an NHS dentist for themselves, prompting their decision to seek private dental care. This highlights the potential scarcity of available NHS dental practices in the area, which can pose challenges for individuals in accessing affordable dental services.

Establishing a Fun Oral Health Routine:

Despite the challenges faced, the individual prioritised their daughter's oral health. They successfully established a routine for brushing and went the extra mile by providing different brushes, timers, and apps to make the process enjoyable for

their child. By incorporating fun elements into oral care, they aimed to foster positive habits and ensure a pleasant experience for their daughter.

Proactive Dental Checkups:

The individual's daughter receives regular checkups, facilitated by proactive reminders from the dentist. These advanced notifications allow ample time to schedule and plan appointments, ensuring that necessary dental care is not overlooked or delayed.

Conclusion:

This case study illuminates the challenges encountered when searching for an NHS dentist in a new area, leading to the decision to opt for private dental care. Despite this, the individual's commitment to their daughter's oral health is evident in the established oral health routine and regular checkups facilitated by proactive reminders.

Acknowledging these experiences aids in understanding the importance of accessible dental care options and the role of proactive oral health practices in promoting lifelong oral wellness.

8.1.1.1.6 Healthwatch Oxfordshire

Story 5. "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 there. Because like [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! 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 6. "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 7. "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 Mums.

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 8. "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 children's 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.

8.1.1.1.7 Healthwatch Reading

Story 9. Dental care and special needs: a parent's perspective

Background

Parent A is a mother to a 7-year-old child with special needs, including a visual impairment. She assists her child with daily tasks such as feeding and toileting.

Oral care at home

Parent A talked about her son requiring assistance with teeth brushing for at least the next 5 years and how he now thankfully cooperates with her. Initially, her child would resist brushing; biting down on his toothbrush making it difficult to brush his teeth. However, they found success with a routine where her child leans against her chest while she holds his head up and brushes his teeth.

“He likes it. He is used to it, and he lets me brush his teeth.”

Parent A gets support and guidance on helping her child with oral hygiene from a family friend who also has a child with special needs.

Access to dental services

Both parent and child are registered with a local NHS dentist, but her child now receives dental care from the community dental service due to special needs. Although accessing regular check-ups was initially challenging, her child now sits calmly during appointments, with Parent A attributing this to the supportive environment that the community dental service offers compared to general dental practices.

Despite knowing the importance of early dental visits, Parent A did not start routine check-ups for her child until he was 3 years old. This was due to her belief that her child did not need to because he did not eat solids until he was 15 months old. Parent A has seen the dentist 3 times in the last 2 years for routine check-ups. She feels the lack of appointment reminders contributes to irregular dental visits as she only books them herself when she remembers.
Parent A recalled a hospital visit due to her child having tooth decay. Her child was anaesthetised ready for tooth extraction but at closer inspection, it turned out to be discolouration. They polished her child’s teeth instead.
Parent A emphasised the need for education on diet and easy access to NHS dental services for children's oral health success.

“[It’s about] what they eat and what they drink, mainly because that can decay the teeth. So healthy eating. Plenty of water and regular checkups [are what is needed.]”

Conclusion

Parent A's experience highlights the importance of tailored dental care for children with additional needs. There needs to be greater awareness and access to the local community dental service, along with further guidance and support for families on maintaining good oral health.

Story 10. Caring for children's oral health: a parent's perspective

Background

Parent B has two children aged 2 and 6 years old. Both do not have any health conditions or special needs. Parent B shares her experiences and challenges in maintaining her children's oral health.

Dental care at home

Both children brush their teeth independently, with Parent B supervising. She encourages them to brush for two minutes, though this can be challenging as her eldest child rushes and does not brush his teeth well. Despite not always following the recommended brushing time, Parent B is not overly concerned as her child brushes his teeth three times a day.

As a medical professional, Parent B uses her knowledge, information and resources from the internet and television programmes to educate her children about oral hygiene. She constantly reminds her children about the importance of brushing, although they do not fully understand its significance, and it can be hard to explain. For example, she mentions that her eldest child’s teeth are changing, and her child told her, “Mum don’t be worried they will grow up and then another one will fall out, and then another one will grow in its place.”

Access to dental care

Parent B and her oldest child are both registered with a local Reading NHS dentist however her youngest child is not due to the practice not taking on any new NHS patients. Parent B believes in keeping the family together under one dentist for easy management.

Parent B and her family regularly attend routine check-ups, and the dentist has suggested potential braces for her eldest child, in the future. Parent B has had both positive and challenging experiences with dental care in the last two years,

including a hospital referral for tooth extraction for her eldest child who loves eating sweets as his tooth broke and became painful.

Hospital experience

Parent B tells us of a bad experience when a dentist at the local hospital advised extracting 10 of her son's teeth, at the age of 4. Parent B was in shock and concerned about what that would mean for her child particularly when eating without 10 teeth. She was told by the dentist, "Oh don't worry, how do babies eat – you are making the food in the blender." Parent B told the dentist "No thank you, you can remove three teeth which are critical – but the other teeth which have started to be broken are not critical teeth." In the end the dentist removed 3 teeth only. Apart of that experience, she does not have any issues accessing dental services, and her child's teeth are okay. However, Parent B feels dental appointments could be more child-friendly compared to her experiences of dentistry in her homeland.

Parent B also registered with a dentist within 3 months of arriving in the UK 2.5 years ago due to her son's toothache at the time, when he was 3 years old. However, her youngest child is still awaiting NHS registration due to the family dental practice not taking on any new patients.

Suggestions for improvement to children's oral health

Parent B suggests shorter waiting times for NHS registration. "I don't know why registration for NHS patient is so long. It takes so long to register as an NHS patient. I don't understand the politics of this country. They take private patients but not NHS. What do we do if we have pain? If you have money – okay, you can fix your teeth…" Parent B also emphasised the importance of prioritizing children's dentistry with longer appointment times. "But I know that time is money…. but still, they need time with children."

Parent B fears neglecting children's dental needs, and if they are not given the priority, could lead to widespread oral health issues in the future: "[…] in about 20 years, we could have a nation full of adults with broken and decaying teeth."

Story 11. The impact of Covid: A difference in dental access for siblings

Background
Parent C is a mother to two children aged 10 and 4 years old. She supports and supervises her youngest child to look after their teeth and gums.

Accessing dental services
Parent C expressed frustration over the difference in dental access for her children. Her 10-year-old is registered with an NHS dentist, while her youngest, born during the COVID lockdown, hasn't seen a dentist due to NHS dental

practices not taking on new NHS patients. She believes this disparity is due to limited NHS access post-lockdown.
Parent C recalls the importance of young children visiting the dentist. She first took her eldest child to the dentist at the age of 2 years old, and though he initially resisted (would not open his mouth), he became comfortable with regular visits. Her son also learned about dental care at nursery school.
Parent C recalls a helpful resource pack she received for her eldest child called 'Start for Life' which included baby books at her local health centre.

"When child 1 was born, we got a lot of booklets and advice from the health centre. But the booklets you get from the health centre you don't get now since covid...Whereas, with child 2 I had none, but for child 1 I got all the advice."

Parent C believes her youngest son's crooked teeth result from not being able to register with an NHS dentist and missing out on vital dental advice. However, she also suspects it may be due to his use of a dummy when he was younger, which she calls "dummy teeth."

"His teeth have all gone funny from his dummy but there is no one to advise me on what is best for his dummy teeth. Like he's got no bite, but he's not gone to see a dentist."

Parents C spoke of repeated cancellations of dentist visits for her older child. When she was eventually offered a new appointment but could not make it, the family were deregistered – herself and her oldest child. She was not told this had happened at the time of turning down the appointment. It was only when she called her dental practice to rebook that she became aware.

They've cancelled twice. So, he's got no dentist appointment now. So now I'm having to ring around to find another dentist because I can't keep going back...For reasons, we have to cancel on the 13th. So, I called and rebooked to the 15th. 'Hi. Really sorry. But for things out of our control, we have to cancel your appointment on the 15th.' Then I got a letter saying, 'our records show that x is due a teeth check'. But in 6 months, they've cancelled twice. So, we only had a dentist for my oldest child. But now they have cancelled twice we have to find a new one for him as well. So, I now need to find an NHS dentist, to try and get all 3 of us in there. 'Cos I'm not in

there either…. Because I haven't been since covid, they've rubbed me off."

Parent C remains concerned that if there was a dental emergency with her youngest in the future, as he will have not experienced going to the dentist before. Post-lockdown she reports that her son is not good with new situations and people, including working with new staff at his nursery.

Recommendations

As a result of Parent C's experience with the NHS dental service post-covid, Parent C has made the following recommendations:

- Have access to an NHS dental practice that accepts herself and her children as a family unit.
- Strategies are needed to address the long waiting list for new registration and appointments.
- Address the repeated cancellations to show parents dental practices care about children's teeth.
- Appointments should be flexible in offering alternative days and times due to children's school hours and parents' availability due to work commitments.
- There is a need for more child friendly dentists and more provision to be provided at school i.e dental visits to schools.

"There is peace of mind for mums like they've come home with a little sticker from the dentist."

- Develop a family friendly dental centre for children or areas in dental practices.

"You can picture it. Nice and bright and colourful – just to make it an experience. Not too daunting for kids."

Appendix 3: Experiences of asylum-seeking families in Oxfordshire

During the project, Healthwatch Oxfordshire accompanied an oral health practitioner from Community Dental Services CIC (www.communitydentalservices.co.uk) to two local hotels housing asylum seekers. They spoke to families about their oral health concerns and about access to dentists and dental appointments. Although not limited to children, the themes discussion topics and observed poor oral health indicated a clear need for further action. Following this, Healthwatch Oxfordshire convened a brief online roundtable discussion in April 2024 with commissioners, and dental professionals, and local refugee support group to link up, share learning and link up towards a more joined up approach around this group. The flexible commissioning scheme was proving successful where information and support was being given. Building on insights from their own listening and from others, they identified the following barriers to NHS dentistry and oral health support among refugees and asylum seekers:

- 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 barriers
- 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 with, and feed into, the wider BOB ICB refugee health support network.

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