

Using dental services with Special Educational Needs and Disabilities (S.E.N.D)

Experience of patients with a Special Educational Need or Disability using dental service in Leicester and Leicestershire.



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Special Project report: Patients with a S.E.N.D. and access to Dentistry

Healthwatch Leicester and Healthwatch Leicestershire (Healthwatch) are the local independent voice of the public in the delivery of Health and Social Care in Leicester and Leicestershire. We collect feedback from members of the public about their experiences of using health and social care services. One of the ways that feedback is collected is through carrying out Special Projects and the findings are shared with service commissioners and service providers to influence service improvements.

The subject of a Special Project is chosen based on experiences shared by the public and conversations with the local authorities.

This project was undertaken to understand the experiences of those using dentist services or their carer/family, with a Special Educational Need or Disability (SEND).

Dyslexic friendly and large print versions of the report are available upon request.

Background

Healthwatch attends community groups, and scrutiny boards as part of its work to understand people's experiences of the health and social care services they use. By attending these forums and listening to feedback provided by the public it became apparent that the experiences of people with SEND when visiting the dentist could be very different.

People's experiences either seemed to very good, with dentists building rapport and explaining what was going to happen, or very negative, for example someone with autism was faced with a dentist in full protective equipment on entering the dentists' room which very frightening. This experience is captured in more detail as part of the report.

To better understand how people with SEND find visiting the dentist a special project was raised by us. Special Projects allow Healthwatch to focus on more specific themes or issues. They are chosen in different ways. It could be the general public, or a volunteer organisation have highlighted something we would like to gather more information on. Sometimes in discussions with local authorities or other strategic partners they tell us areas they would like to know more about. Projects are then agreed between our commissioners and the Healthwatch Leicester Healthwatch Leicestershire Board.

What We Did & Why

As part of this project a survey was designed to capture peoples' overall experience when visiting the dentist. This included things that people with SEND find helpful when going to the dentist as well as problems they may face. The survey enabled us to capture feedback in an anonymous way and could be shared widely across Leicester and Leicestershire.

A QR code was developed that allowed individuals to access the survey online. This was circulated at events and was an effective method when used at the Local Offer event and the Hidden Disabilities event.

3 interviews were also held with the parents of a children with SEND and one interview with a child. This enabled us to explore in more detail people experience of going to dentist and find out any issues that had been encountered and how these may have been avoided.

Who Took Part

25 people completed the survey. The demographics of those who took part can be found in Appendix A. Due to the small number of people who completed the survey we can't draw any conclusions from the demographic information, so no analysis has been carried out, but the information is included for your information.

One child, 2 women and 1 man were individually interviewed.

Key findings

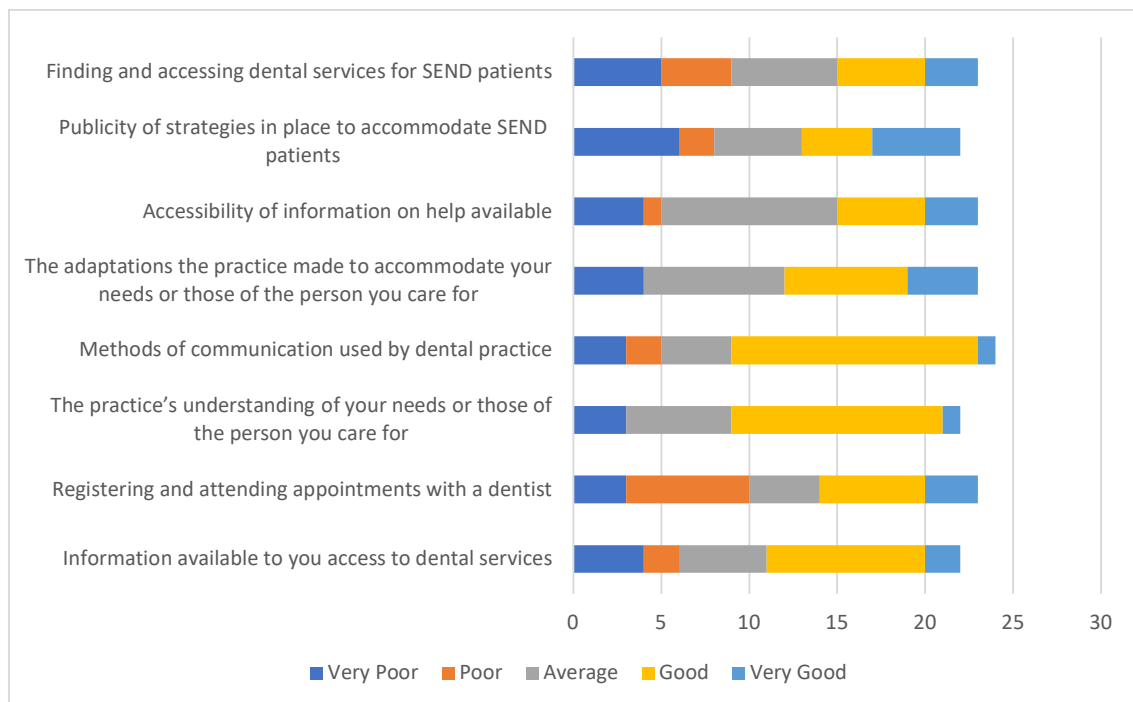
Survey Results

The survey consisted of 3 main sections aimed at gaining an understanding of people's overall experience when accessing dental services. Each section had a series of statements that people were asked to rate from very good to very poor. Additional information was captured in a comments box at the end of each section.

Not everyone who responded to the survey completed all the sections. All information provided has been captured below.

SECTION 1

Please rate your experiences of various aspects of accessing dentistry services for yourself or the person you care for.



- 9 of the 23 respondents (39%) advised the experience of finding and accessing dental services for SEND patients to be poor or very poor. This is reflected in 10 out of 23 (43%) respondents advising they had a poor or very poor experience of registering and attending appointments with a dentist.
- Publicity of strategies in place to accommodate SEND patients (was the plan for SEND patients made public) was rated poor or very poor by 8 out of 22 (36%) of responses. This rating however also got the most "Very Good" responses with 5 out of 22 (23%) indicating this may depend on the dentist you attend.

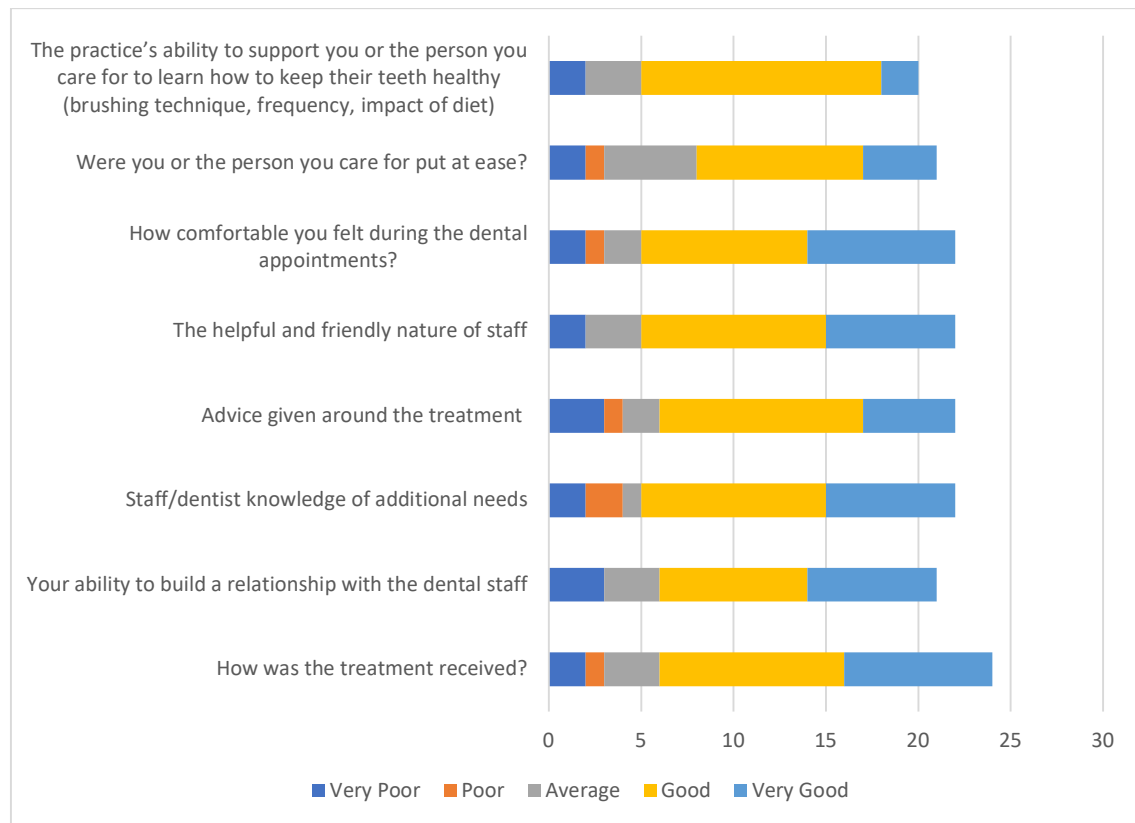
- Accessibility of information (being made aware of information and how easy it is to understand) on help available was rated by 18 out of 23 (78%) respondents as being average, good or very good. Whilst information may not be readily available, when it is it seems to be accessible.
- 13 out of 22 respondents (59%) felt their practice have good or very good understanding of their needs or those of the person they care with 11 out of 23 respondents (48%) also stating that adaptations the practice made to accommodate your needs or those of the person you care for were good or very good. This illustrates that where a practice has a good understanding of a patient's needs, they are also adjusting for that person.
- Methods of communication used by dental practice such as text messages or telephone calls were also responded to positively with 15 out of 24 (62%) responses being good or very good. This section had the highest number of "Good" responses with 14/24 (58%).
- Information available to you access to dental services had a very split response. 8 out of 22 (37%) advised a poor or very poor experience. 5 out of 22 (23%) advised it was average and 11 out of 22 (50%) said it was a good experience. This could show that more can be done to inform people on how to access dental services.

Additional comments and information for section 1 - comments have been unchanged

- ❖ NHS dentist - I registered myself, helpful, friendly accommodates change of room due to stairs, same dentist each time specialist dentist used - referral system via early years, used 2 dentists 1st - one older friendly but daughter not so happy with treatment 2nd - younger - very good extremely helpful great experience trust developed
- ❖ Don't go a lot. Nobody tells me
- ❖ I get given all the suitable information needed for when I go for a dentist appointment. The dentist gives me all the correct information for when I go
- ❖ OK but nerve racking

SECTION 2

Please rate the treatment and support that you or the person you care for has received throughout their treatment plan.



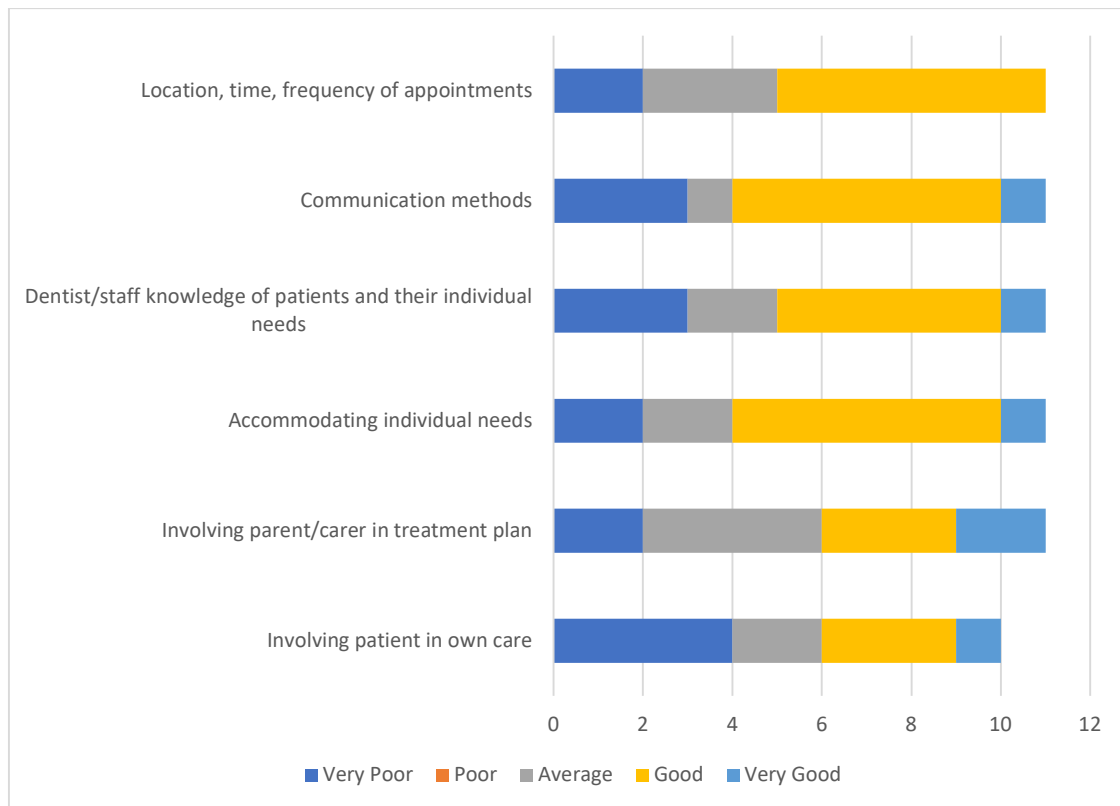
- The practice's ability to support you or the person you care for to learn how to keep their teeth healthy (brushing technique, frequency, impact of diet) was rated good or very good by 15 out of 20 (75%) of respondents.
- 18 out of 25 (72%) advised how they received treatment to be good or very good. Advice given around treatment reflects this with 18 out of 22 respondents (73%) advising advice was good or very good, however 4 of the 22 respondents advised this was poor or very poor showing marked level of disparity on advice given by dentists on treatment received by people.
- How comfortable people were made to feel during appointments was rated as good or very good by 17 out of 22 (77%). This is reflected in people being made to feel at ease. 13 out of 21 (62%) said this was good or very good.
- 17 out of 22 (77%) advised that staff/dentist had a good or very good understanding of their additional needs. 4 (19%) people however advised they feel is poor or very poor again showing a disparity between experiences.
- When asked how friendly staff are 17 out of 22 (77%) advised this was good or very good.
- This links into people's ability to build a relationship with their dentist. 15 out of 21 people (71%) said this was good or very good. No one said this poor but 3 people (14%) said it was very poor.

Additional comments and information for Section 2 - comments have been unchanged

- ❖ The dentist I go and see takes a close look at my teeth and says I am doing very well at brushing properly. He gives me the right advice when I need to know what I need to improve on.
- ❖ Nobody supports me cos I don't go anymore

SECTION 3

Please rate any issues or examples of good practice that you have experienced with your dental practice or for the person you care for.



This section received fewer responses than the previous 2 sections with a maximum of 11 people answering a specific question. As most questionnaires were completed in waiting areas before appointments, it may be that people ran out time to complete it before being seen by the dentist.

- This seems to be the most polarised section which reflects what we have seen in the previous sections around good and bad experiences. On the whole people had a good experience or a very poor one when it came to issues or best practice.
- Location, time and frequency off appointments was felt to be good or very good by 4 out of ten (40%) of people. The same amount however felt it to be very poor.

- 7 out of 11 people (63%) advised communication methods were good or very good but 3 people (27%) said they felt this was very poor.
- Involvement in their own care was rated
- 6 out of 11 people (55%) advised that they felt good or very good about the staff/dentists understanding of their individual needs. This isn't as high as in the previous section, but this may be because less people completed Section 3. It is similar to the number of people who felt good or very good about the accommodation of their needs. 7 out of 11 people said this was good or very good (64%)
- Involving a person in their own care or involving a carer/parent in a treatment plan was less favourable. 4 out of 10 (40%) advised involvement in their own care was very poor. Involvement of a carer or parent in a treatment plan was better with 2 out of 11 (18%) advising this was very poor.

Additional comments and information for Section 3

- ❖ Getting to know the person and building trust before any treatment begins. Showing equipment and feel/touch before treatment begins. Remember the person and talking about what they enjoy doing & their likes
- ❖ Never been contacted about joining a dentist
- ❖ Good information and comments given on my teeth
- ❖ They always talk to mum about treatment, impact of diet. No information is given to patient with needs

Survey Considerations

The survey was shared online through the Special Educational Needs and Disability Information Advice and Support Service (SENDIASS) and through our own social media, also with key NHS and Social Care partners (LA, UHL, LPT, CCG) who sent out through their networks. Feedback we received from respondents did suggest possible improvements to the survey, which has been taken onboard for future surveys.

Dentists were also approached and encouraged to ask people to fill in the survey. One problem with this approach was that it is not always obvious if a person has a special educational need or disability and it was difficult for dentists to identify people to answer the survey.

- ❖ Healthwatch will use these considerations to improve survey design and circulation for future projects.

Interviews

4 interviews were held as part of this project. 3 were with the parents of a SEND person and 1 with a child with SEND. 2 interviews are included in the report, one with a parent and one with a child. The other interviews can be found in Appendix C.

The information below has been anonymised, but as much as possible the words have been kept.

Child case study

This interview concentrates on the experience of a child with SEND visiting the dentist. They were interviewed with a parent.

This child visits 2 dentists. A general dentist and a specialist. They don't mind the general dentist but hates going to the specialist. The child had a bad experience when they received fluoride treatment. They "hated" the taste. The child was very adamant about how much this was disliked. That experience has triggered a negative feeling towards going to the dentist.

Even just brushing the child's teeth is difficult. They don't like the feel of the brush in their mouth. Mouthwash stings so they don't like using it.

Would be interested in using the mouthwash used at the dentist as it has a milder taste and they like the colour.

When asked how involved the child feels when going to the dentist, they weren't sure. Feels like they talk to the parents but not to them. Would like to be talked to more. When visiting a hygienist for the first time, the hygienist took time to talk to the child. This made them feel much more comfortable and the appointment went well. If time could be taken by dentists to talk to the child at appointments and they agreed a plan and the dentist would understand what the child likes and doesn't like this would make them feel better about going to the dentist.

Interview with a parent

This interview was with a parent whose child is non-verbal autistic.

The child's school said they needed to find a dentist. The parents weren't given any advice on how to do this or where to go but wanted to find a dentist that the child was comfortable with. The child 5 years old and they wanted somewhere that feel comfortable. The parent found a general dentist and explained their child has non-verbal autism. The receptionist said that would offer "stuttered sessions" until the child was more comfortable. They had a couple of sessions and the child wasn't comfortable the situation. The dentist has full protective equipment and didn't talk to the child at all. The parent explains you could tell the dentist was scared. As the dentist was anxious this made the child more anxious. The parent and child could both hear the conversation

between the dentist and dental assistant. The parent says, “it was more like handling a dog or something that was gonna bite you and all the headgear and stuff”.

The parent spoke to the practice about this very uncomfortable experience but felt “dehumanised” when trying to talk about it. The parent knew the dentist didn’t want to see them again. The parent is annoyed because if the dentist was hesitant about seeing them, he would have preferred that the appointment was cancelled, and they had been referred to the specialist SEND dentist. As a parent they feel let down. This very negative experience has now it much harder for their child to feel comfortable about going to the dentist.

Due to this experience the parent wanted to find their child to a different dentist but wasn’t sure how to go about it. The parent spoke to Healthwatch about this experience. It was after speaking to us that the parent became aware of the specialist SEND dental service.

The child is now 7 and still struggles at the specialist SEND dentist but is getting better. The specialist gives the child time to look round room and get comfortable. They talk to him directly. The dentist is reassuring even if he doesn’t get to look the child’s teeth and says they can try again in 6 months. The dentist is good at providing different brushes and pastes trying to find something the child likes.

This parent suggests it might be better for young children with SEND to go to the specialist first. If they get on ok there, then they can go to a more general service. Also suggests better training for reception staff. The receptionist had been told that the child is autistic but was asked very few questions about what accommodation might be needed.

Conclusion

Although the survey is from a small sample, we can still draw some common themes from the information. Whilst people's experiences can be very different, overall, most experiences seem to be good. People feel that the treatment they receive is good and most dentists seem to have a good understanding of a person's needs and accommodate people with SEND in a way that makes them feel comfortable when attending appointments. There are however some people who perceive the service they are receiving as very poor. This is either because they don't attend a dentist at all (12%) or because when they do, they have a negative experience.

Trying to find a dentist and register with one seems more difficult. 9 of the 23 people (39%) found the experience of finding and accessing dental services for SEND patients to be poor or very poor. This is reflected in 10 out of 23 (43%) respondents advising they had a poor or very poor experience of registering and attending appointments with a dentist.

The interviews highlight how one negative experience can affect a child's relationship and perception of going to the dentist. Even when the experience is ok it can still be "nerve racking". Quicker referrals to the specialist service and advertising the self-referral process could mean that people with SEND have a positive experience of dentists from the start.

Both the survey and interviews highlight the importance of communication with a dentist and building rapport. The interviews particularly show what a difference someone taking time to talk to a person can make to their experience. Ensuring patients are spoken to about their treatment and feel involved with what is going on makes a big difference to how they experience the dentist.

On the whole whilst some people have a good relationship with their dentist it is clear that others either aren't attending the dentist or when they do have a very poor experience which can affect their view of dental services for a long time.

Recommendations

These recommendations are based on the survey results and interview.

- Taking time to talk to a person before an examination or treatment can make a real difference to how it is received. Even if a person can't communicate with a dentist it doesn't mean they don't understand what is being said to them.
- Information on the specialist SEND dentist should be more widely available. This could be advertised in waiting areas, GP's could talk to people about the service at annual SEND check-ups or schools could be made aware of the self-referral process to raise awareness of this specialist service and let people know how to access it.
- Additional sounds, smells and tastes at a dentist can make visiting the dentist overwhelming for people with SEND. Small changes could be made, for example finding out what fluoride flavour someone can tolerate, would make a big difference.
- If a dentist feels they have not had the right level of training to be able to attend a person with SEND, it would be better if another dentist examines that person. Dentists should feel comfortable in attending SEND patients, so training could be provided more widely.
- Reception staff could also be provided with more training to ensure a person's needs are better understood before they visit the dentist. Where dentists understand a SEND, person's needs they are good at making them feel comfortable during appointments. 59% said dentists were good or very good at understanding their needs of these 92% went on to say the dentist was good or very good at making them feel comfortable. If reception staff felt better able to ask questions around people's needs this would help people's experiences.
- Links between GP's and Dental Services should be better established. This way dentists might be able to identify SEND people in their area and reach out to them rather than a person having to register themselves.
- It should be highlighted that NHS 111 can be used for dental emergencies

Next Steps

Westcotes Specialist Dental Service could provide best practice information to other dental services within Leicester and Leicestershire. This would benefit general practices and also make them aware of when to make referrals.

Whilst Healthwatch Leicester and Healthwatch Leicestershire made every effort to include Leicester and Leicestershire in this project, based on the post codes provided by respondents most surveys were completed by people living in Leicester City. Further work could be carried looking more at experiences of people living in the county.

This report will be shared with the following Boards and Organisations.

- ❖ Local Dental Network
- ❖ Oral Health Protection Board
- ❖ Leicester City Parent and Carer Forum
- ❖ Leicester City Council
- ❖ Leicestershire County Council
- ❖ Care Quality Commission
- ❖ Leicester, Leicestershire and Rutland Clinical Commissioning Group

Thank You!

Healthwatch Leicester and Healthwatch Leicestershire would like to thank all the participants who helped with this project. Without you this project would not have been possible.

Appendixes

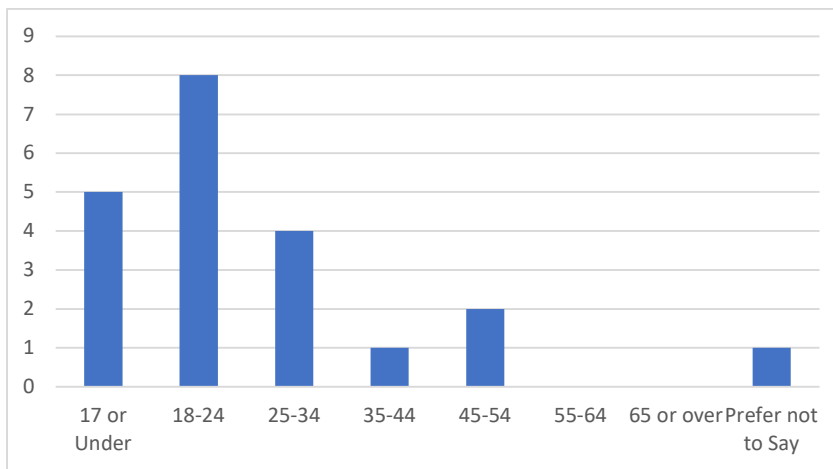
Appendix A – Survey Demographics

All demographic information that was completed is captured below. Some participants chose not to complete this section.

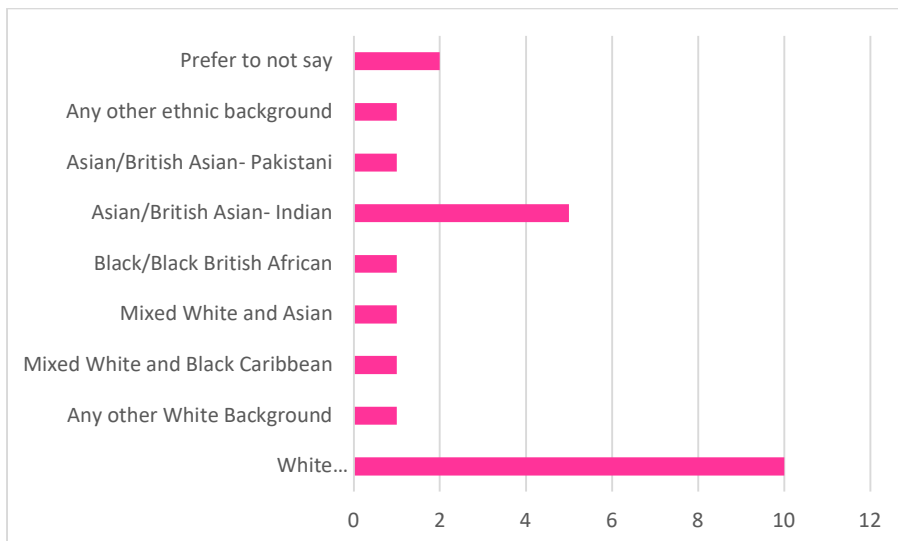
1. What is the first part of your postcode?

Post Code	No.
LE1	1
LE2	5
LE3	4
LE4	3
LE5	2

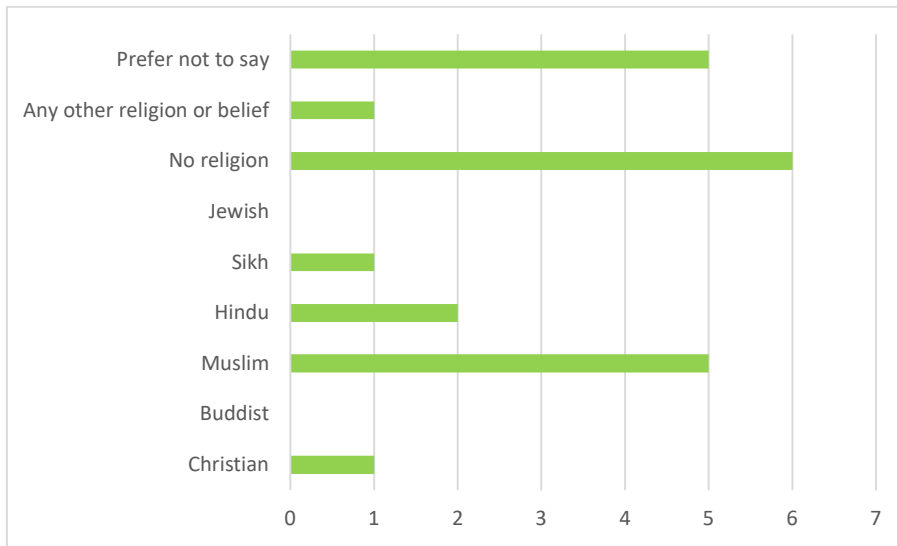
2. What age group are you in?



3. What ethnic background do you identify as?



4. What is your religion or belief?



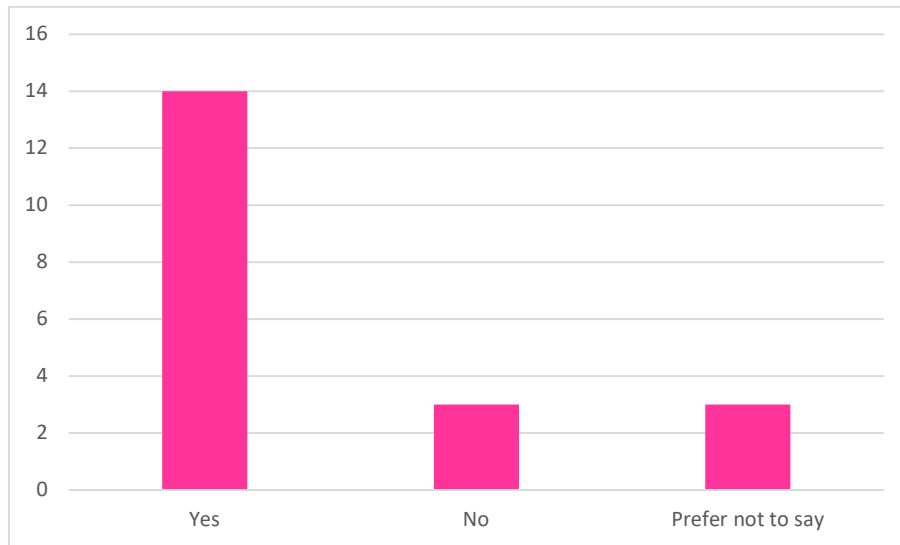
5. What is your marital status?

Married	1
Civil Partnership	1
Single	13
Divorced	1
Separated	0
Widowed	0
Co-habiting	0
Prefer not to say	4

6. What is your sexual orientation?

Heterosexual	9
Homosexual	0
Bisexual	0
Other	0
Prefer not to say	10

7. Do you consider yourself to have a disability or long-term condition?



Appendix B – Full Comments

All the comments that people left for each section are shown below. The comments have not been changed in anyway.

SECTION 1

Please rate your experiences of various aspects of accessing dentistry services for yourself or the person you care for.

- ❖ Very hard after they stop cater for the person who has learning difficulty for one issue or other. There's not much dentist who takes on for special adult
- ❖ NHS dentist - I registered myself, helpful, friendly accommodates change of room due to stairs, same dentist each time specialist dentist used - referral system via early years, used 2 dentist 1st - one older friendly but daughter not so happy with treatment 2nd - younger - very good extremely helpful great experience trust developed
- ❖ Don't go a lot. Nobody tells me
- ❖ Doesn't attend a dentist
- ❖ I get given all the suitable information needed for when I go for a dentist appointment. The dentist gives me all the correct information for when I go
- ❖ OK but nerve raking

SECTION 2

Please rate the treatment and support that you or the person you care for has received throughout their treatment plan.

- ❖ The dentist I go and see takes a close look at my teeth and says I am doing very well at brushing properly. He gives me the right advice when I need to know what I need to improve on.
- ❖ Nobody supports me cos I don't go anymore
- ❖ Fantastic
- ❖ Nobody signs

- ❖ My dentist is brilliant
- ❖ I don't go

SECTION 3

Please rate any issues or examples of good practice that you have experienced with your dental practice or for the person you care for.

- ❖ They have poor appointment system when they do not send an appointment
- ❖ Getting to know the person and building trust before any treatment begins. Showing equipment and feel/touch before treatment begins. Remember the person and talking about what they enjoy doing & their likes
- ❖ Nobody contacted me about dentist
- ❖ Never been contacted about joining a dentist
- ❖ Good information and comments given on my teeth
- ❖ They always talk to mum about treatment, impact of diet. No information is given to patient with needs
- ❖ I have no issue
- ❖ Tells me my appointment after the treatment and gets me in straight the way for emergency
- ❖ There are no issues at present

Appendix C – Interviews

Below is a summary of the additional 2 interviews carried out as part of this project.

1. Interview with a parent

This interview was with a parent of 3 children. The second child has downs syndrome.

The child goes to the dentist without any problems.

The child had some cavities but wouldn't let the dentist look properly. The dentist was very patient and referred them to Leicester Royal Infirmary (LRI) where anaesthesia was given to have them removed.

Overall, the dentist has been very good. Always sees them if the parent is worried about something. They always see the same dentist. He has developed a good rapport the child. Asks about school and has a small conversation before the appointment starts.

As a parent they weren't sure if the dental practice has a plan for people with SEND but felt they were doing a good job naturally.

The dentist they attend is a general practice. This parent hadn't heard of the specialist SEND dental service but would like more information in case it is needed in the future.

2. Interview with a parent

In this interview a parent talked about their child's experience.

They use 2 dentists. A general one and a specialist paediatric dentist. The child is quite comfortable with the general dentist. They go there for check-ups and see the same dentist each time. The dentist talks to the child and explains what he going to do.

At first the child was comfortable with the specialist paediatric dentist, but then they had a fluoride treatment. The fluoride was toffee flavoured and the child really dislikes sweets things. This experience means that now just the mention fluoride “makes her jump out the chair” and the child refuses to have it.

The child is particular about how things feel in their mouth. Doesn't like foaming toothpaste or anything with a strong flavour. The parent has found a toothpaste from Japan that doesn't foam as much but hasn't had advice from her dentist on where to get something similar in the UK.

The parent feels like they have to go to 2 dentists as the general practice will only do a check-up. The specialists will do a proper clean. The child has a heart condition, so they have to be very careful with the cleanliness of the gums.

They saw a hygienist recently who they haven't seen before. This went well because the hygienist took some time before treatment to talk to the child about books they liked.

More generally, access to emergency dental services were also discussed. Only recently did they find out you can use 111 for emergency dental issues and thinks this should be better advertised.

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