

Family Voice Norfolk Consultation on Access to Dental Services

Consultation

Parent carers of children and young people with special educational needs and/or disability (SEND) were consulted via an online survey in August 2020 about access to dental services.

Background

Family Voice Norfolk (FVN) is a collective of parent carers from over 1,050 families across Norfolk and represents nearly 1,400 children and young people with SEND. FVN has been the strategic voice of parent carers working in partnership with Norfolk County Council (NCC) and the Norfolk and Waveney Clinical Commissioning Group (CCG) since 2006. It is funded through a direct DfE grant (administered through Contact), by NCC and by the CCG.

Parent carers were invited to complete a questionnaire online and had the opportunity to include comments on their experiences on access to dental services. The survey ran for only one week over the school summer holiday from 11 to 18 August 2020. FVN received 86 responses, representing 90 children and young people (CYP) with SEND.

What did we learn?

Several key themes emerged from what parent carers told us and to a certain extent applied whether NHS, specialist or private dentists were accessed. Almost all the issues were a feature of accessing dentistry *before* Covid-19, but the pandemic has certainly made them more widespread.

Communication of information about services and about patients is poor:

- 70% of respondents did not know if their CYP was eligible for referral to a specialist dentist.
- 63% did not know who could make such a referral
- many non-specialist dentists do not seem to have accurate information about what services are available
- parent carers are asked to fill in the same lengthy paperwork each time instead of being asked just for changes
- dentists do not use parent carers' knowledge, advice and experience ("they need to listen to parents and treat them as key in ensuring that treatment outcomes are successful for children")
- since lockdown, little information has been given to families about plans for future appointments.

Dentists' understanding about SEND needs to be better:

- dentists seem to have little training about SEND and in particular that CYP are individuals and that a 'one-size fits all' approach will not work (again, ask parents...)
- in particular, there needs to be better understanding of ASD and sensory issues
- the need for extra time and a calm approach is not sufficiently understood
- a positive approach is essential ("Don't ever say to us I don't think he'll manage that without giving him a chance!" "With the right support, time and effort even the most terrified children can receive necessary dental care.")
- taking time to explain what will happen to CYP in an appropriate way is key – not talking to the parent only and ignoring the CYP
- written information, dual texts to CYP and parent carer, everyone working together for better outcomes – there are many approaches that would help
- something that may not be an emergency in dental terms may well be an emergency as far as family life, other behaviours and the CYP's wellbeing are concerned.

There are some systemic issues that have a big impact:

- consistency is key – never seeing the same dentist twice adds tremendously to difficulty
- frequently cancelled appointments, or irregular appointments, add to parent carers' stress, even if CYP are unaware of them – a parent's stress so often adds to a CYP's stress
- CYP at special school may be around an hour's travelling time from home; appointments that would be less disruptive of an entire day would help
- private dentistry, a solution for some families, is expensive and beyond the reach of many, particularly when the CYP becomes an adult
- in many areas it is almost impossible to find an NHS dentist willing to take on a new patient, especially one with SEND
- there is not a consistent picture across Norfolk – in some areas appropriate dentistry is extremely difficult to access
- long waits for referrals and appointments leave families in limbo – sometimes for years rather than months.

Examples of good practice are hugely appreciated:

- hospital treatment received praise ("They would do well to learn from experiences at the Norfolk and Norwich oral health team and their excellent children's disability nurse.")
- all staff, including receptionists, need to be calm, patient and non-judgemental
- positive reinforcement with stickers etc. works well for many CYP
- reception areas need to be quiet and not crowded
- there is no sense of rush and that the CYP and/or family is a 'problem'.

The appendices to this report give direct comments from parent carers, including alarming reports of parents feeling forced to attempt dentistry themselves (fillings and extractions) when unable to get an appointment since March. Others report deteriorating oral health in vulnerable CYP because it has not been possible to access appropriate dentistry for many months. We are also concerned that our respondents were those who were actively accessing or failing to access dentistry for their CYP. Those who do not consider dentistry an essential part of care for their child will not have felt that this survey was relevant for them.

Key messages

- 70% of parent carers do not know if their child or young person is eligible to be referred to a specialist dentist and 63% do not know how to get a referral for their child or young person.
- A third of parent carers, who are waiting for a referral, have been waiting for over a year to see a specialist dentist.
- Parent carers are being subject to frequent changes in names of, locations and appointment times for specialist dentists making it incredibly difficult to see a dentist.
- Over a quarter of parent carers said that they would like a dentist to visit their child in school.
- Over 60% of parent carers said that visiting a dentist was not a good experience for either them or their child or young person with a further 12% saying that either they or their child did not have a good experience of the visits.
- When asked how they felt visiting the dentist, 53% of comments mentioned that they and/or their child felt stressed, nervous and/or anxious.
- 80% of parent carers would like to see more specialist dentists in Norfolk.
- 10% of parent carers needed an urgent dentist appointment for their child or young person during the Covid-19 pandemic but only two parent carers received care for their child.
- One parent carer had to personally give their child a temporary filling on two occasions. Both fillings fell out.
- Nearly two-thirds of parent carers have had appointments for their child or young person cancelled since March 2020 and only 15% of them have been given any indication of when their next appointment will be.

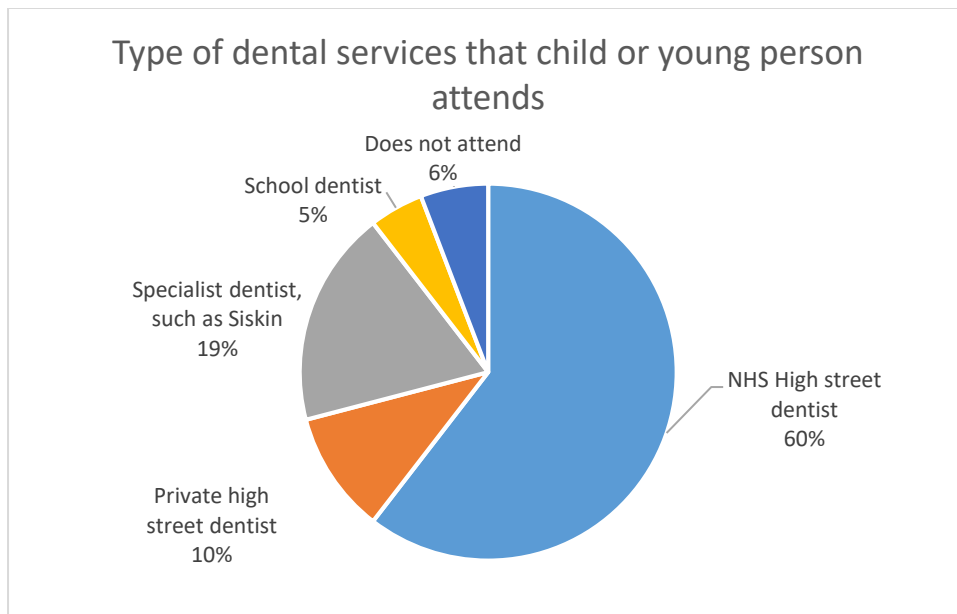
Access to dental services works well for children and young people with SEND when:

- Dentists have an understanding of the child's individual needs. Children and young people with an Education, Health and Care Plan (EHCP) already have information in a document that could be shared with dental staff;

- Parents and dentists explain to children and young people what is about to happen and what equipment will be used;
- There are consistent, calm, non-judgemental and patient dentists and staff within the dental surgery;
- There is positive reinforcement for children and young people, with stickers and treats at the end of the examination;
- Reception areas are quiet and uncrowded;
- Appointments are not rushed;
- Appointments are not unnecessarily cancelled;
- Parents do not feel blamed for not looking after their child's teeth;
- Parents and young people are not required to fill in the same forms at each visit;
- Parents are informed of and involved in any changes to young person's dental care, such as texting appointment times to both the parent carer and the young person.

Main findings

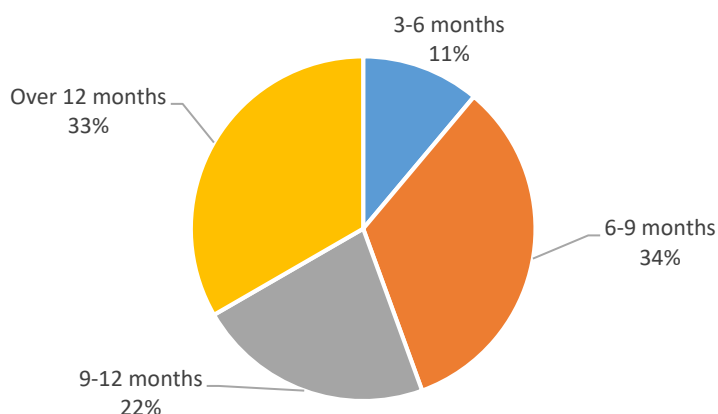
The chart below shows that 60% of children and young people attend an NHS high street dentist, 19% attend a specialist dentist specifically for children and young people with SEND, and 5% see a dentist while at school.



Of the 6% of children and young people who do not attend a dentist, one parent carer did not know where to start to find a dentist, one is waiting to see a specialist dentist, two children are under school age and one is over 17 years old.

Parent carers were asked if they knew if their child or young person was eligible to see a specialist dentist. 70% of parent carers did not know if their child or young person was eligible to be referred to a specialist dentist and 63% did not know how to get a referral for their child or young person.

Waiting time for a referral for a specialist dentist



Currently, 11% of parent carers have a referral and are waiting to see a specialist dentist. As no new referrals have occurred in the last five months due to Covid-19, all children and young people have been waiting for longer than three months. Parent carers are being subject to frequent changes in names of, locations and appointment times for specialist dentists making it incredibly difficult to see a dentist, while their children and young people suffer with infected teeth and not being able to see a dentist. A third of parent carers, who are waiting for a referral, have been waiting for over a year to see a specialist dentist.

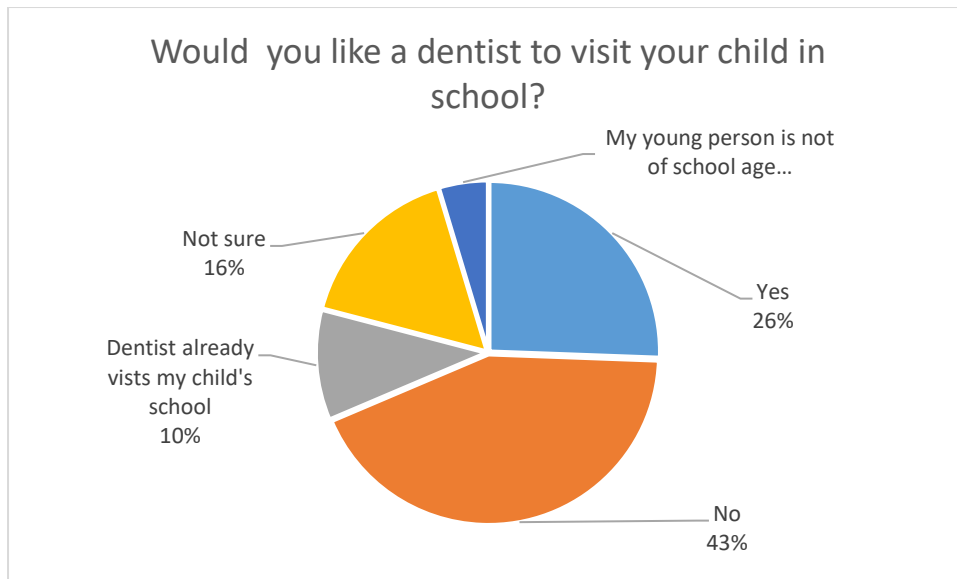
Comments from parent carers:

“Waited a year for a tooth extraction under a general anaesthetic at the hospital. Siskin couldn't help. Child had repeated infections in tooth and antibiotics multiple times. He has acid reflux, which damaged molars..”

“My young person had teeth removed and fillings put in via Newberry clinic (at Gorleston) at the end of 2019. A follow up appointment was made in 2019. This was cancelled and an appointment made for January 2020, due to them moving to Lowestoft. That was then cancelled again. And another made. This has since been cancelled due to COVID 19. The filling has now come out.”

Please refer to appendix A on page 10 for full comments from parent carers waiting for a referral to see a specialist dentist.

Parent carers were asked if they would like a dentist to visit their child in school. Over a quarter said that they would like this and 43% said that they would not. Many parent carers wanted to be present with their child to help alleviate anxieties with visiting the dentist so felt that school dentists would not work. However, comments from parents that would like to see dentists in school said that it would be easier for them and their children to have access to dental services in a familiar environment.



Comments from parent carers who would like their child to see a dentist while at school:

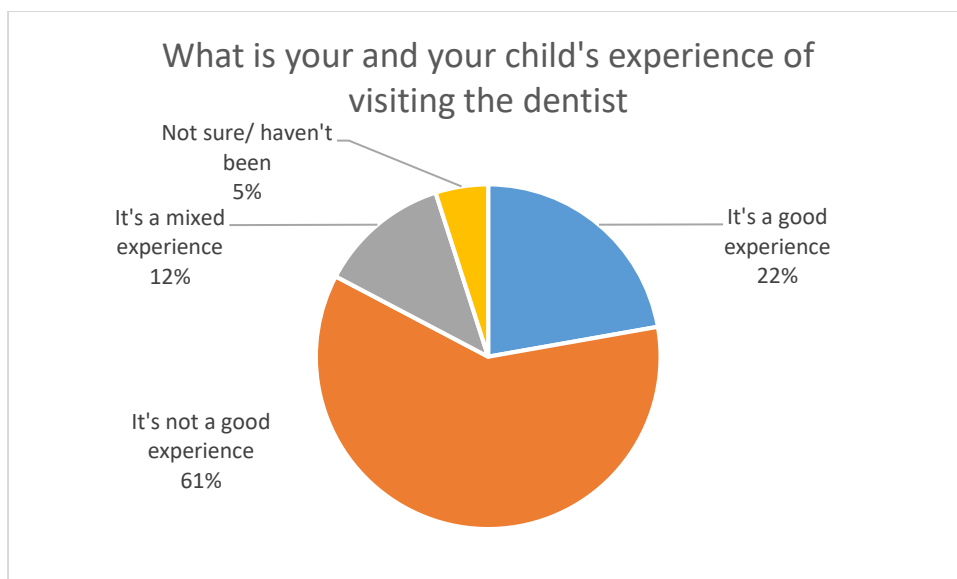
“It would be extremely helpful if a dentist could visit the school. The hardest part is in the waiting room, my child doesn’t understand what we are doing and what is about to happen and can get upset/agitated with the wait, especially if there is a long wait due to previous appointments over running. Appointments at school would help as the wait would be eliminated as the child can stay in class until the dentist is ready for the next child.”

“Easier to access and less disruptive rather than miss school. It's familiar surroundings with familiar people which make it less scary.”

Please refer to appendix B on pages 11 to 12 for full comments from parent carers on dental services being provided in schools.

Parent carers were asked how they and their child or young person felt when going to the dentist. This was summarised into it being a good, not good or mixed experience (where parent carers and children reported differing experiences). Over 60% of parent carers said that visiting a dentist was not a good experience for either them or their child or young person with a further 12% saying that either they or their child did not have a good experience of dentist visits.

When asked how they felt visiting the dentist, 53% of comments mentioned that they and/or their child felt stressed, nervous and/or anxious.



Comments from parent carers who don't have good experiences with dentists:

"I am always stressed about the wait that could happen in the waiting room. This can cause my child to get upset/agitated which can then impact on the actual appointment." – Specialist dentist

"He feels very anxious as he has to wait a long time between appointments, some dentists don't understand autism and don't take the time he needs to make him feel at ease." – NHS dentist

"My YP feels nervous as he has a hearing impairment yet the dentist keeps asking him questions with his mask on. Have explained many times that my son can't hear so well or lip read through the mask. I can't sign as my son is lying down. This was the pattern every time we went. This was before Covid!!." – NHS dentist

"She's afraid and I'm anxious." – NHS dentist

Comments from parent carers who have good experiences with dentists:

"She's well prepared as the dentist has a good understanding of her autism and is very accommodating." – NHS dentist

"Our specialist service is fantastic. He is happy, they explain everything, he can explore the equipment. Happy mum and young person." – Specialist dentist

"Relaxed in the knowledge that we are going to an understanding and patient dentist." – Specialist dentist

Please refer to appendix C on page 13 to 15 for full comments from parent carers on dental services being provide in schools.

Parent carers were asked what works well for them and their child when attending the dentist. The comments in the appendix are split by type of dental services but the same themes appear from NHS dentists, private and specialist dentists. Please refer to appendix D on pages 16–17 for full comments. The main themes are:

- Dentists that have an understanding of the child's individual needs;

- Parents and dentists that explain to children and young people what is about to happen and what equipment will be used;
- Consistent, calm, non-judgemental and patient staff within the dental surgery;
- Positive reinforcement for children and young people, with stickers and treats at the end of the examination;

Parent carers were also asked what does not work well for them and their child when attending the dentist. Please refer to appendix E on pages 18 to 20 for full comments The main themes from parent carers comments include:

- Busy and noisy reception areas;
- Dentist not understanding the child's special needs;
- Not having the same dentist each time;
- Rushed appointments;
- Parent feeling blamed for not looking after child's teeth;
- Having to fill in the same forms at each visit;
- Parents not being informed of changes to young person's dental care when they are not in the room with them during their appointment;

When asked, 80% of parent carers would like to see more specialist dentists in Norfolk.

Access to dentists during Covid-19 pandemic

10% of parent carers needed an urgent dentist appointment for their child or young person during the Covid-19 pandemic. Of these, only one parent carer found it an easy experience, with one more actually getting an appointment. One parent carer had to personally give their child a temporary filling on two occasions. Both fillings fell out. The remaining parent carers were not being able to access dental services for their child or young person during the Covid-19 pandemic.

Comments from parent carers:

"No, it was an awful process. She needed a filling and twice I had to try and fill it myself, which of course didn't work. I finally managed to get her to see a dentist where they agreed to do a temporary filling but already this has half come out. I understand the issues around Covid-19 of course but the practices in places seemed a little overboard and ultimately frightening for my daughter. As a hospital ward-based physiotherapist, I am acutely aware of the infection control practices required but the harsh military appearance of the dental environment and stern attitude of the staff were unnecessary."

"It was difficult trying to get an appointment. And when got one they were unable to complete the correct treatment resulting in her still waiting for a vital appointment due to filling falling out both sides of mouth again and now suffering pain and swelling. They gave me antibiotics yesterday after calling them over a month ago about the temporary fillings they had put in on original emergency appointment falling out and if my daughter is in pain it must be bad as she tends not to feel pain. She always has drilling and fillings done without injections."

"No, we were denied treatment- filling lost on front tooth and as not in pain no treatment"

"Haven't been able to be seen yet."

Nearly two-thirds of parent carers have had appointments for their child or young person cancelled since March 2020 and only 15% of them have been given any indication of when their next appointment will be.

Final comments

Parent carers were asked if there was anything that they would like dental service providers to know about their child or young person's experiences of dentists. Nearly 60% of parents left comments. A summary of these are below and all the comments can be found in appendix F on pages 20 to 22.

Comments from parent carers:

“People with ASD are generally more anxious so need longer to help them not be rushed. If rushed due to time constraints my child never gets a good check-up.”

“I feel that there is not enough awareness of special needs in dentist and they don't know how to handle a situation if it happens so then the child doesn't get treated properly.”

“Considering that the Siskin centre is meant to be the experts at treating children with disabilities they would do well to invest in some more training for their staff, their approach is very wrong. They should have a social story that can be emailed out to all new patients and most importantly, they need to listen to parents and treat them as key in ensuring that treatment outcomes are successful for children. They would do well to learn from experiences at the Norfolk and Norwich oral health team and their excellent children's disability nurse. With the right support, time and effort even the most terrified children can receive necessary dental care.”

“I feel that dentists, like schools and hospitals/GP's should have a care plan for SEN people (young and old). This plan would outline any difficulties, which would guide the dentist and staff in the care of the person.”

“Appointment times etc. texted to both of us would be useful. My daughter would feel in control and I would be able to do the working out of logistics that she cannot do.”

Finally, parent carers were asked for their final comments. A summary of these are below and the full comments are in appendix G pages 23 to 24:

Comments from parent carers:

“A specialist dentist would be amazing. Didn't know about this until recently despite difficult ineffective check-ups. We have just brought it up with our child paediatrician. They have requested GP referral but have heard nothing yet, so no referral as far as we know.”

“I have enquired about special needs dental services with my own practice to no avail. I feel all children with SEN should be informed of any specialist dental services available.”

“I wanted my son to see a dentist during lockdown due to an adult tooth growing over the baby tooth, but I was told it was not an urgent issue and I couldn't get him seen. We had to pull the tooth out ourselves, which led to meltdowns.”

“There does not seem to be a huge amount of knowledge regarding SEND in the NHS dental service.”

“More SEND individuals would be happier to attend if they had a care plan for the dentist.”

“Only seems to be one place in our area and so difficult to get an appointment.”

“So many factors affect SEND children's ability to look after their teeth. It becomes a daily battle. I would like my child to have more frequent appointments to clean and maintain teeth, as a preventive.”

“We need more dentists that understand our complex children and give more time for appointments when necessary. Dentists need to be fully wheelchair accessible,”

“I do not know where to start in finding a dentist.”

86 parent carers responded to the survey and their responses represented 90 children and young people with SEND.

	Mainstream	SRB	Special School	Home school	Other	Total
0 to 4 years old	4%	0%	0%	0%	0%	4%
5 to 11 years old	29%	6%	19%	3%	0%	57%
12 to 16 years old	2%	1%	13%	0%	1%	17%
17 to 21 years old	7%	0%	6%	0%	2%	15%
22 to 25 years old	2%	0%	0%	0%	5%	7%
TOTAL	44%	7%	38%	3%	8%	100%

Appendix A

Please add any comments relating to the time you have been waiting, such as any notifications you have received since or before Covid-19.

- I was told by my NHS dentist that my diagnosed son was attending, that he would need to see a specialist dentist due to his behaviour during the last appointment. They was going to put him forward for a referral and I haven't heard any more since
- My young person had teeth removed and fillings put in via Newberry clinic (at Gorleston) at the end of 2019. A follow up appointment was made in 2019. This was cancelled and an appointment made for January 2020, due to them moving to Lowestoft. That was then cancelled again. And another made. This has since been cancelled due to COVID 19. The filling has now come out. I have rung the place at Lowestoft since the country has allowed dentists to do some work and he is now on a list. But the dentist are moving again, The filling is not the smallest and is on one of his front teeth.
Young person has various learning difficulties including ASD and being deaf plus a fear of the dentist.
Routine dental appointment with normal dentist has also been cancelled which was in April. Have no idea when the next one will be. I feel as if my son had been forgotten by the specialist team, considering he had had teeth removed and there should have been a follow up appointment to make sure everything healed and went ok. Clearly it hasn't, as he has lost a filling
- My daughter has been waiting to see a community dentist since last year and I was told that at the moment they are only seeing emergency patients
- My daughter attended our dental practice in April 2020 and I was advised that she needed a back tooth removed. I called the Siskin, which I was advised had changed and that her referral would be dealt with the Norwich/Bowthorpe Centre, or whatever complicated name it's been given, but by all accounts from others is actually the same place?! They advised that the referral had been issued on incorrect paperwork so they couldn't help. I have been back and forth sooooo many times to both parties to get this resolved but to absolutely no avail and the tooth is now mouldy and has now affected her other tooth and is causing her much discomfort. But I seem to be getting absolutely nowhere with anyone. And we have heard nothing from our own dentist since Covid and have obviously also missed our annual check-up.
- Waited a year for a tooth extraction under a general anaesthetic at the hospital. Siskin couldn't help. Child had repeated infections in tooth and antibiotics multiple times. He has acid reflux, which damaged molars.
- My son had to wait around 1 year and a half for dental extractions

Appendix B

Please let us know why you would or would not like a dentist to visit your child in school.

Dentist already visits my child's school

- Good to be in a familiar environment and puts child at ease knowing their classmates are seeing dentist as well
- Good to have regular check ups

My child or young person is not of school age

- Because she has an enamel deficiency and having problems seeing dentist for important check-ups leading now to her having holes in both sides of mouth where fillings have fell out and her being in pain and swelling.
- The dentist did visit when he was at special school

No, I would not like the dentist to visit my child in school

- My child is less anxious about things when I am there
- Already have a dentist
- As far as my kids are concerned school is school and dentist should be separate
- As he attends the dentist with me and I can discuss his teeth with the dentist. If at school, I may not receive this information, as my son cannot be relied upon to pass on any information.
- Because I want to choose an appropriate provider
- Because I would want to be present. Also in adulthood, my child will need to see a dentist in a real setting.
- Because we go as a family which seems less stressful for him.
- Child likely to find it very stressful
- Happy with the service we already receive
- He is used to seeing the dentist in his surgery now so I wouldn't want to change what he's used to doing.
- Heighten anxiety
- I think he would find that confusing
- I want to be present and at school they are not firm enough with him
- I would prefer to be with my child at appointments like this
- My child is autistic and is dental phobic.
- My child is home educated
- My child would hate the public nature of a school dentist, queueing up, being seen as different etc. by peers if this was a specialist service for those with additional needs.
- My daughter has always gone to the dentist and that is where she expects to see a dentist, I think if a dentist visited her at school this would confuse her
- My daughter has various teeth issues so I prefer to be present at appointments. Also it would induce a lot of anxiety.
- My son gets very stressed about visiting/seeing a dentist I would want to be with him when he is seen to comfort him.
- My son is 21yr old goes to college. At the moment, he seems ok visiting dentist practice .It depends on the dentist he sees. Last year we changed dentists as the person we saw acted rudely and was very abrupt. My son got upset and refused to go there again. I made a complaint. The dentist was aware of my son's special needs.
- My son now starting college and won't want to look different. He is fine with his existing dentist.
- My son would find this out of context and would struggle with this as school is school and the dentist is the dentist in his view.
- No reason to visit child in school. I would rather she goes to the actual dentist.
- Our dental practice is just down the road from where we live. The dentist we see is very good with our son who has special needs

- School is a safe place and I would not want this disrupted by the anxiety of a dentist visit
- Too much anxiety for them
- We as parents prefer to be present so we can understand any areas of concern

Not sure

- I'm not sure how she would cope with that, and how would I be informed of any issues if they were to visit her at school? I always try and book dental appointments in the holidays so that it doesn't affect her school day.
- May be confusing to my child and would need preparation to cope.
- Not appropriate due to autistic behaviour
- Not sure how she would respond
- School dentist does go in once a year I think but I am not sure whether they get to look in his mouth.
- The dentist office is just around the corner

Yes, I would like my child to visit a dentist at school

- Because my NHS dentist consistently cancels check ups
- Convenience of not attending dentist
- Easier to access and less disruptive rather than miss school. It's familiar surroundings with familiar people which make it less scary.
- Familiar surroundings, support from t/a
- He'll be going to a specialist setting an hour away from home, would save him time out of school
- In school would allow flexibility as general appointments have to wait until holidays
- It would be easier as we wouldn't need to prepare for a actually appointment as my child gets incredibly anxious and worked up about visiting the dentist
- It would be easier than attending the practice as it would be part of the school day. I only would like this when Covid 19 has gone.
- It would be extremely helpful if a dentist could visit the school. The hardest part is in the waiting room, my child doesn't understand what we are doing and what is about to happen and can get upset/agitated with the wait, especially if there is a long wait due to previous appointments over running. Appointments at school would help as the wait would be eliminated as the child can stay in class until the dentist is ready for the next child.
- Less disruption for an autistic boy
- More familiar surroundings
- offer advice and diet advice and to help the children that can access a dentist
- Time saving, familiar environment for child
- To build a relationship and to ease his anxiety.
- To show the importance of cleaning teeth and not just eating the toothpaste!
- Yes it would be nice seeing other children having check-ups that might calm her down
- We are home-schooled so it would be in our home :)
- School visit would be better as not always able to get son out once he's at home.

Appendix C

How do you and your child or young person feel when they go to the dentist?

Good experiences with NHS high street dentists

- As he's got older it's been easier. He was surprisingly good while having a full mouth brace fit for 2 years
- Fine
- Fine
- Fine and calm.
- Fine as Dentist is ok and our daughter is excited about going.
- Quite calm -never been a problem despite ASD, ADHD and high anxiety
- She likes the dentist
- She's well prepared as the dentist has a good understanding of her autism and is very accommodating
- very welcome
- We're always made to feel welcome. The dentist puts my child at ease and explains to our Son what he is going to do before he does it

Mixed experiences with NHS high street dentists

- He feels okay. I feel nervous that he may require any treatment other than a check up, which hasn't happened yet. He doesn't react well to pain.
- I feel more nervous than my child
- My child feels okay but doesn't want to stay long
- My son quite enjoys the experience as it's a trip out and a sticker at the end. He has not experienced pain yet!! He does struggle with the sensory side, bright lights and close proximity of the dentist to his face.
- Seems OK going a little nervous at times
- She is ok. She does not like having injections for work done and has fillings done in past with not injections.

Not good experiences with NHS high street dentists

- Anxious
- Anxious
- Anxious
- Anxious
- Anxious
- anxious
- Anxious.
- Don't look forward to it. Waiting room difficult. Then difficult to get her properly checked. We have always gone but not sure she has ever had a good effective check.
- He feels anxious and needs to be prepared for the appointment.
- He feels very anxious as he has to wait a long time between appointments, some dentists don't understand autism and don't take the time he needs to make him feel at ease
- He is very anxious as has sensory issues around his mouth. We have been to Siskin dentist before, but may possibility to referred again in the future if any work needs to happen.
- I feel anxious and child gets stressed with the long wait you normally have as dentist seems to be always running late. This can cause meltdowns in the waiting room.
- It is quite a stressful affair as we go as a family and any noise is not tolerated.
- My child gets very anxious about going to the dentist and gets upset or refuses to have anything in his mouth
- My daughter feels very anxious
- My son experienced a high level of anxiety during his last check up which resulted in a meltdown. This then puts me under a lot of stress and anxiety
- My son gets really upset about going to the dentist he has hyper mineralisation which means his teeth are really sensitive and weak so doesn't even like air being blown onto them.

- My YP feels nervous as he has a hearing impairment yet the dentist keeps asking him questions with his mask on. Have explained many times my son can't hear so well or lip read through the mask. I can't sign as my son is lying down. This was the pattern every time we went. This was before Covid !!
- Nervous and anxious with stress
- Nervous and very agitated
- Nervous because our previous NHS dentist was very abrupt and unfriendly
- She feels anxious and so becomes very excitable and loud when at the dentist
- She's afraid and I'm anxious
- Sometimes stressed
- Stressed sometimes
- Unhappy
- Very anxious
- Very anxious, worried, scared, nervous
- Very nervous , as pressuring child to conform and wear braces , struggles with dental hygiene, dentist quick to respond negativity
- Young person is very anxious to the point doesn't want to go
- My daughter doesn't like to be touched or examined she has been diagnosed as ASD
- My child is so anxious she is crying saying she doesn't want to go and curls in a ball in the corner of the dental room
- I try not to make a big thing about it so that it doesn't cause anxiety. She's only ever had a check up and never had any work done so I was wondering how she may feel or might be once this tooth is removed.
- Never got chance because they always cancel

Good experiences with private dentists

- Fine

Mixed experiences with private dentists

- Not a problem now that he is older. Had some tricky times (stressful) when he was much younger.
- He loves it!! I hate it!!

Not good experiences with private dentists

- A bit anxious
- My child finds going to the dentist very very difficult. The Siskin centre has been dreadful, we have been working really slowly with a private dentist and she is now able to walk into the private dentists and speak to the dentist although will still not let her teeth be examined
- Anxious
- I feel stressed as my young person finds this extremely hard. The sensory issues mean anything in her mouth is uncomfortable
- Nervous. Son getting better as now seen by a dental surgeon at our private dentist.
- Worried

Good experiences with school dentists

- Fine
- OK

Not good experiences with school dentists

- When he has seen a dentist it was very stressful. They were due to send a follow up appointment out and never did.

Good experiences with specialist dentists

- Fine
- Fine

- Our specialist service is fantastic. He is happy, they explain everything, he can explore the equipment. Happy mum and young person.
- Relaxed in the knowledge that we are going to an understanding and patient dentist

Mixed experiences with specialist dentists

- I think he is ok but the bright lighting and strong smells can overload his senses
- My son is ok but doesn't like to return to school afterwards.

Not good experiences with specialist dentists

- Both very anxious
- Great fear of the dentist
- Greatly increases child's anxiety
- He is extremely anxious and overwhelmed...I feel it's stressful for me too.
- I am always stressed about the wait that could happen in the waiting room. This can cause my child to get upset/agitated which can then impact on the actual appointment
- Lots anxiety.
- misunderstood
- Our child is apprehensive to open mouth once sat in the chair despite countless tactics being employed
- Slightly anxious

Child or young person does not attend a dentist

- My son does not currently have a dentist
- Not been
- Fine no anxiety.

Appendix D

What works well when you take your child or young person to the dentist?

NHS dentists

- Nothing
- Dentist is understanding of his needs, does procedures slowly and allows him time to sit upright when he feels the need
- A friendly dentist
- Preparation
- Quietly supportive
- A dentist who understands my child's needs
- When the dentist explains exactly what they're going to do and show him the instruments etc.
- Calm and friendly dentist.
- Not having to wait too long in a waiting room
- Going first thing in the morning so quieter with less waiting. Checking teeth is still difficult.
- If they are given a sticker
- Talking about it before
- Reading books in the waiting room while we wait.
- Gets a good check-up and our daughter enjoys the attention and experience.
- Talking about it so he is prepared. Giving an incentive after.
- That we both go into the room together.
- Sometimes a bribe of having a Costa hot chocolate afterwards!
- Him being able to stay in his wheelchair
- Going in on time. We also take a phone for him to play on so he is distracted.
- Unsure
- That our dentist has always been the same person and she has had him since she was very young. We're also never in there very long.
- Letting my daughter see me having my check-up.
- Atmosphere in dentist is calm and quiet.
- Whilst we wait he watches YouTube on my phone. He likes it when he gets a sticker at the end
- Haven't found it yet
- Me being present. Kind and jolly dentists who make her feel at ease and explain in slow simple terms what they are going to do.
- A tablet (computer)
- Not much, the dentist always fails to even manage to apply fluoride. We have been several times to try and have fissure sealants applied without success. The dentist says the community dentist for children has a long waiting list and wouldn't do preventative work that my son needs.
- Me taking him and supporting him. Offer of a sticker at the end, making sure the dentist is aware of his needs and the needs to be quick.
- There isn't really anything positive about my YP's experience of going to the dentist.
- Me their parent having a check-up at the same time, all the family gets done together in the same appointment
- Calm demeanour, clear language, ways of acknowledging the way she already cares for her teeth
- Same dentist and staff each time.
- Our dentist is really friendly and patient and he says what he is doing.
- Our dentist is very understanding of her being autistic and so reassures her and explains what she is doing
- For me to see what they are doing and explain. Also to keep talking to her and reminding her to keep her mouth open as it seems to slowly close whilst they work in her mouth.
- Calm, quiet, well explained procedures and minimal waiting.
- The dentist let's her try the tools beforehand and tells her what is happening every step of the way

- Examinations with slight clean
- When it is very quiet and there is no one else in the waiting area, and when appointment is actually on time rather than late!
- Very little
- Calm surroundings and patient staff.
- Talk to them before about what is likely to happen, tell them how proud I am of them, offer a reward if treatment is needed
- Understanding
- Everything
- The waiting room is usually quiet and cool
- I am allowed to go with them, prepared in advance what is happening, talked to my child on the day
- With the new dentist we have visited once, all was ok . Will see how it goes in the future. It took me whole day to find new dentist. Its very difficult to find NHS dentist.

Private dentist

- I stay with him and keep reassuring him
- Visual story. Reassurance, same dentist, same room, same routine, knowing what will be expected in advance.
- We are given extra time for appointments but have to pay privately which seems so unfair
- The friendly personality of our dentist
- The dentist is a younger guy and played music and films for him
- If the dentist and all staff involved are aware that my young person has ASD with sensory issues. Also the anxiety it causes both of us
- Time. Space. Fast appointments. Attitude of dentist
- His knowing the dentist and feeling comfortable with her.
- Dentist understands child's needs

School dentist

- Firm approach
- They talked to the child which reassures them

Special dentist

- Thorough investigation
- Not being judged as a parent and being patient and kind with child
- So talking, calm and a friendly person her
- Staff friendly
- Regular appointments which haven't happened
- The dentist is understanding and patient, the appointment can vary in length depending on mood of my child
- The staff are lovely and thorough
- The spinning chair.
- They will listen
- I use PECS to inform him and the dentist needs to know the boundaries
- Not sure as hasn't been overly successful as we haven't had a dentist available for a long time
- Everything
- The reception area is not crowded and staff there "understand"
- Have a parent present
- OK
- I changed to a special needs dentist as the private dentist i use to take her to couldn't cope with the way she is.

Appendix E

What does not work well when you take your child or young person to the dentist?

NHS dentists

- Dentist refused to see her that's why he has done a referral to a community dentist
- Sitting in waiting room with lots of other people
- A dentist that isn't familiar with autism
- Dentist not being clear in communication
- Talking too much. Rushing him.
- A noisy waiting room. A dentist who doesn't introduce themselves or speak clearly, addressing my child, letting them know what they will do as they go. Not asking questions when they have instruments in my child's mouth as this causes anxiety as my child then doesn't know what to do!
- Not always seeing same dentist
- Long delay after appointment time
- When it's busy. When the dentist changed and we have a new person to try to work with.
- If they don't get a sticker
- Cancellations
- Having a long wait.
- Dentist may be a little afraid of doing much i.e. scraping scale etc.
- Sprinting it on him without discussing it for the previous week.
- Having to explain his autism, ADHD and dyspraxia to the dentist each time of when the dentist changes/ leaves without any warning.
- Dentists not having sufficient training with autism, clinical environment, not enough time in the appointment!
- He finds it hard to keep his mouth wide open.
- The waiting time
- No dental work usually done but can imagine difficulties when it has to be
- Surgery is often running late so for a child on the spectrum that can be an issue along with it being very, very busy. Also, there seems to be issues with the referral process for a child having to have work carried out.
We were advised that she would be seen within 18 weeks of a referral having been made which has long gone pre Covid and that would only be for an initial consultation with the specialist and then she would have to wait yet again to have the tooth removed this has and will cause her anxiety.
- Noise upsets the receptionist!
- Keep getting different dentists who don't know my child and his disabilities. Consistency would be nice.
- If he needs to have anything put in his mouth he will not want it the dentist will then just leave it
- Dentist not being ASD sensitive
- Dentists who are impatient and don't understand my daughter's special needs, anxieties and sensory issues.
- There is not enough time in the appointment, it is obvious the dentist is annoyed because he has over run his time by the time my son co-operates to open his mouth.
- Any change of routine.
- I'm trying to help my YP be more independent but the dentist is one of the places where my son needs the most support. He gets very anxious before going
- When we can't be all done together and the waiting time in the waiting area is far too long.
- Fear mongering, unclear language, talking down to her
- Sometimes the wait in the waiting room.
- Before she was diagnosed the dentist would be impatient with her which heightened her anxiety
- Them not being able to complete vital dentist work because of lack of correct PPE.
- Noise, being rushed and not having things explained pre procedures
- A change of dentist - ours is retiring
- Waiting & extractions
- Busy environment, late appointments,
- Everything

- Lots of noise or more than one person talking to my child.
- No preparation, no sympathy, rushed
- Negativity , teeth not brushed correctly, voice tone
- Nothing
- Our son is not very good at having to wait. If we do have to wait, there is nothing for him to do.
- Surprise treatment they are unaware of in the day, Noise of the machines
Understand language of dentist
- Dentist understanding special needs children and adults.

Private dentist

- It taking too long
- Pressure, however well meaning, to do something our daughter is not ready for. Not understanding that the parent is the expert on their child with special needs and listening to what they have to say about the best way of treating their child.
- When they are told something negative!
- If things move too fast and it is rushed. Also if the dentist does not talk or does not explain enough.
- Medical language. Too much information.
- Would probably not work as well if we changed dentist or if he needed an invasive procedure.

School dentist

- Letting him touch everything and saying that he's alright
- New people, new room, lack of understanding about needs from dental staff

Special dentist

- Nothing
- Parent being blamed for not looking after child's teeth. Dentist talking to parent and not child directly
- 1. Having to pay for car park when you don't know how long the appointment/delay before appointment/waiting time is going to be. Impossible to tell whether the free 20 minutes will be enough.
- 2. I encourage my 23-year-old to go into the actual dentist's room by herself as an increase in independence appropriate for her age. I wait just outside. However, she is often asked to sign something that she has no idea about (does she get contributory ESA, for example). The result of putting the wrong thing could be an enormous amount of extra expense and hassle. Surely, dentists can understand that being able to sit in a chair and engage sufficiently with a dentist does not mean that you have an understanding of complex benefit information? My daughter has a visible learning disability.
- 3. Every time we have to fill in the same form about health etc. Could they not supply the last form and ask if anything has changed? Or even not supply the last form and simply ask if anything has changed since the last appointment? She isn't going to suddenly not have a congenital chromosomal disorder. They could check she has not moved house like the hospital do, just by asking. Or they could ask us to input the info digitally on a screen so they don't have to check through it all again.
- If it's not the same dentist
- Usually running late which increases child's anxiety
- Big gaps of time between appointments. November was the last time he was seen even though he's got a referral to Siskin.
- The waiting room especially if there is a long wait.
- Constant form filling which does not have enough space for his complex medical needs and extensive list of medications.
- Having their mouth looked in.
- bright lights and regimented approach
- Delays in getting in, changes in who dentist is.
- Waiting for a long time to be seen as always running late

- Parking as busy location
- If they are running behind time wise
- Haven't had that problem

Does not attend a dentist

- My son was under the community dentist/Siskin until he was 17. Then a dentist (without me being present as I was waiting outside) told him she thought he was able to attend a mainstream dentist and took him off the list. She did not tell me. When no appointment arrived for his next time, I rang up to ask and was told then. I do not think that dentists are necessarily qualified to know whether a YP's social communication difficulties will or will not affect their ability to attend a mainstream dentist. They reinstated my son because he was under 18 and they should not have delisted him, but after the next session he was told again to go and find his own dentist. There is no way that he has the ability even to know where to start. I tried on his behalf but could find no NHS dentist willing to take him on and who he could access by public transport. He cannot possibly afford a private dentist. They required over a hundred pounds just to assess him. He is an adult and now in work (which is wonderful) but there is still no way that he can afford private dentistry and aspire to live independently in any way. He receives annual learning disability health checks and PIP (and neither of these are given for no reason) yet the dentist decided he was able to access mainstream services. With support to find someone (who would understand, for example, that he takes language very literally and will promise whatever anyone asks him to, but not do it) he perhaps could, but not by himself. He has a congenital heart condition (and is under the care of the cardiology department at NNUH) and bulimia (and is under the care of dietitians at NNUH), both of which increase the importance of regular dental check-ups, but this seems not to be important either. There must be many young and older people like him falling through gaps because of the lack of joined-up care for those who do their very best to manage independently but are vulnerable and at risk without some support.

Appendix F

Is there anything that you would like service providers to know about your child or young person's experience of dentists?

NHS dentists

- My son does not absorb information quickly. He needs short simple sentences. Speak slower, calmly.
- Keep child with same dentist that knows him and not see different one every time
- Braces and retainers were a problem; due to not being able to keep the retainer in has resulted in teeth crossing again.
- To be mindful of our SEND children and have a quieter area for them to wait
- People with ASD are generally more anxious so need longer to help them not be rushed. If rushed due to time constraints my child never gets a good check-up.
- Generally, our experience has been fairly good, although our daughter does have an anterior open bite due to thumb sucking, which has not been rectified.
- Fortunately, he has only had to have check-ups so his experience hasn't been very negative.
- Surgeries are very clinical, not autism friendly - strange smells, Uncomfortable seating, nothing to interact with e.g. toys. Not enough time for children in appointment. Not given the opportunity to explore surgery or understand the tools that may be used.
- More understanding about the struggles they face and more compassion from the staff
- That she's not had a very good experience so far.
- I feel that there is not enough awareness of special needs in dentist and they don't know how to handle a situation if it happens so then the child doesn't get treated properly
- Telling them off for not brushing their teeth properly doesn't help, they need positive encouragement
- I very much want her to see a dentist who has experience of special needs and the teeth problems they have. A more child friendly environment would work well too.
- That he needs time, that he finds having his teeth played with painful/distressing.
- Not at this time. Things could well change as and when he experiences pain.
- I would like the dentist environment inside to visually be more homely and not so clinical looking and the dentist to have play toys out for all age kids.
- It is so difficult to get an appointment outside school time and often the receptionists are unfriendly
- The NHS availability is awful to access
- The calmer you are and the more patient you are the more reassured she is
- We have not seen dentist properly in a while and when she attended for an emergency end of July and they filled her teeth without drilling because they don't have the correct PPE, the fillings both fell out within a week whilst eating her food.
- Please don't rush,
- More widely available understanding of the needs of people on the spectrum to access/practise the use of tools before an appointment
- Dentist don't generally appreciate what pain autistic children go through during extractions, they may of numbed area but pressure can be just as bad as pain for SEND children. Sedation should be a freely available option. Unfortunately, doesn't appear NHS support this.
- That waiting is an issue, that they may have sensory issues etc. that they need things explaining first sometimes...
- Allow more time for their appointment, talk to the child, take things slowly
- We praise child for independently brushing teeth regardless of effectiveness
- That he and I we are very pleased with our dentist
- Our daughter has been undergoing extensive dental work at the Orthodontics Department of the Norfolk and Norwich Hospital for the last 7 years. The service and treatment she has received during this time has been excellent.
- I think it would be good idea all dentists had to information on our children's problems.

Private dentist

- Considering that the Siskin centre is meant to be the experts at treating children with disabilities they would do well to invest in some more training for their staff, their approach is very wrong. They should have a social story that can be emailed out to all new patients and most importantly, they need to listen to parents and treat them as key in ensuring that treatment outcomes are successful for children. They would do well to learn from experiences at the Norfolk and Norwich oral health team and their excellent children's disability nurse.
With the right support, time and effort even the most terrified children can receive necessary dental care.
- Parents are being forced to pay privately in order to see a dentist who has the time, skill and patience to help the child
- When my child was referred to Siskin it took over two years to be seen, and even then I had to complain to the top people to get the appointment sorted
- Don't ever say to us I don't think he'll manage that without giving him a chance!
- I feel that dentists, like schools and hospitals/GP's should have a care plan for SEN people (young and old). This plan would outline any difficulties, which would guide the dentist and staff in the care of the person.
- Speed up referrals.
- Child has ASD but nearly 17 and much more able to cope now.
- waits are way too long

Special dentist

- My child needed a varnish to prevent staining and was not made aware until he was 11 years old. - also to use fluoride toothpaste earlier- so more good advice given earlier.
- I would love my daughter to be able to learn to access these appointments by herself but because I feel that there is little support for her on the above matters, I dare not do it. She would need, for example, any results or information to be given to her in written form, so that she could share it later and remember and file it. She would need not to be asked to sign something she does not understand. Some kind of meeting between the service, my daughter and me as her carer to establish lines of communication and decision-making would enable my daughter to be more independent and her mother to be less anxious. On other forms (e.g. EHCP) my daughter would spontaneously tick the option of all info going both to her and to me (rather than just to her or just to me). I'm sure she would say the same if offered that option by Siskin. Appointment times etc. texted to both of us would be useful. My daughter would feel in control and I would be able to do the working out of logistics that she cannot do. I don't think this kind of thing is impossible to organise and it would greatly increase the dignity and respect afforded to the patient.
- It has generally been positive but obviously a great deal of pressure on services which makes it harder to access
- They need to have items to engage/distract children in the dental surgery - to make it a more positive experience for SEN children.
- Waiting can be difficult if appointments are not running on time
- Sensory problems, eating and dietary problems, which are causes of decay.
- Refused antibiotic cover at Kings Lynn St James's due to change of NICE policy (ulcer under 2 teeth) but low immunity meant that he should have had it. After weeks, he was dealt with in Norwich after Cardiologist got involved. He then developed heart issues leading to pacemaker being fitted. It was not a good experience!
- Be consistent, ask the child and parent what works best for that child
- Cannot praise the services of community dentist enough. Superb service for my son.
- That it is a much needed specialist service and a godsend to parents who want to have their youngster's teeth checked regularly by dentists who understand their special needs and care for them in an appropriate manner

Appendix G

Please tell us any other comments that you have regarding dental services for children and young people with SEND.

NHS dentists

- A lot of dentists don't understand what autism means and how to make child feel safe and calm
- A specialist dentist would be amazing. Didn't know about this until recently despite difficult ineffective check-ups. We have just brought it up with our child paediatrician. They have requested GP referral but have heard nothing yet, so no referral as far as we know. Would love to see a list of specialist dentist available but as with most things probably more demand than supply?
- As mentioned visually more homely and interactive toys for kids all ages as long waiting time in the waiting room can heighten anxiety if no distractions are provided, maybe a separate room provided if a family or person feels overwhelmed sitting with others in the general waiting room is too stressful.
- Dental services don't seem to know what is happening
- Dentist appointments are often cancelled, sometimes last minute, the dentists at the practice change regularly, my daughter has to come in with me and her younger sister (who has a condition with her teeth) and this causes her anxiety. My daughter's teeth are healthy and she is happy to brush them herself but going to the dentist has become much more traumatic than it needed to be by the receptionist's attitudes and the abrupt nature of one of the dentists. Sometimes we've waited over 6 months for a new appointment after one has been cancelled and when we try to call and rearrange there's a long wait and appoints are not available out of school hours (particularly difficult as my daughter attends school 45min away)
- Dentist is very patient with my son
- Hospital has both my sons' details. If they get taken in, it flags up how best to deal with their needs and of how help and reassure them.
- I as a parent, have no idea that or if I could access specialist services for my child with autism
- I had no idea there were any specialist dentists for SEND
- I have enquired about special needs dental services with my own practice to no avail. I feel all children with SEN should be informed of any specialist dental services available.
- I think my son will be referred if a difficulty with his teeth happened but in the meantime, he stays with a high street dentist. No real work can be done on his teeth, more a case of looking in his mouth and counting the teeth.
- I wanted my son to see a dentist during lockdown due to an adult tooth growing over the baby tooth, but I was told it was not an urgent issue and I couldn't get him seen. We had to pull the tooth out ourselves, which led to meltdowns.
- It would be good to have on the front of the notes the child's condition or SEND need so the could make reasonable adjustments at appointments or just to be aware they have a child or young person with autism.
- No NHS dentist available at my practice since Covid
- Not a clue how they will help because they always cancel appointments
- Sadly told by our dental practice that they would see my autistic son as he wouldn't wear a mask. He is 8 years old. Formal complaint made and apology given by now lost trust in practice.
- There does not seem to be a huge amount of knowledge regarding SEND in the NHS dental service.
- There isn't enough special dentists in Norfolk
- We are generally ok but no specific SEND offered at the practice

Private dentist

- Most dentists do not understand or care in my limited experience

- Rubbish, go private.
- Daughter was due to have a filling in March and have not heard a thing from the dentist
- He has accompanied me since he was born, with his disability it was a process of building trust
- I feel that dentists do not care in general but especially about SEN people. More SEN individuals would be happier to attend if they had a care plan for the dentist. I feel everybody is treated the same at the dentist but it needs to be more individual.
- Siskin need to employ more dentists and improve communication - trying to get through on the phone took 3 hours recently!!!!

School dentist

- Personally not often enough for my son

Special dentist

- Exceptionally poor coverage in our area
- Important to just treat the child as any other but understand their limitations, ask parents.
- My son also has ASD but the Siskin wouldn't see him, but they see both of my girls.
- My son has attended the Siskin Centre for between 15-20 years - because of their specialist service; my son looks forward to going to the dentist and has no fear about going. He always receives the best care there. It is a service, which must NEVER be withdrawn.
- Only seems to be one place in our area and so difficult to get an appointment. They have no flexibility and you get day/time that you are given regardless of whether this means your child taking a whole day off school, or not.
- Our dentist has left and not been replaced. Been waiting for over a year for an appointment. Keep getting told I could go to Norwich but that is over 50 miles away. That would be too stressful for my child.
- So many factors affect SEND children's ability to look after their teeth. It becomes a daily battle, I would like my child to have more frequent appointments to clean and maintain teeth, as a preventative.
- Special service and Siskin are brilliant service for us.
- There is a one-size fits all approach, which isn't uncommon in children with SEND. Over the years, I have had many issues with dental care in Norfolk and although we are under the Siskin Clinic, now there is still a quite inflexible approach and we have to fit in with their way of doing things which is usually not best suited to our needs.
- We need more dentists that understand our complex children and give more time for appointments when necessary. Dentists need to be fully wheelchair accessible

Does not attend a dentist

- I do not know where to start in finding a dentist