

**Thomas N, Blake S, Morris C, Moles DR. (2017) Autism and primary care dentistry: parents' experiences of taking children with autism or working diagnosis of autism for dental examinations. International Journal of Paediatric Dentistry doi/10.1111/ipd.12345/full**

## **Summary**

### *Background*

Accessing and receiving preventative dental treatment can be difficult for children with autism due to sensory processing disorders and/or challenging behaviours, coupled with a reported reluctance by dentists to treat these children.

### *Aim*

To gather dental experiences of UK parents of children with autism and explore how they feel primary care dental services can be improved.

### *Design*

A total of 17 parents of children with a diagnosis or working diagnosis of autism, took part in semi-structured interviews. Data were analysed thematically.

### *Results*

Key themes identified were flexibility of the dental team and environment, confidence of the parents to advocate for their children's needs, continuity of services and clear referral pathways to specialist services. Cross-cutting all themes was the value of clear communication. The experiences provide greater understanding of issues such as, hyper-empathy, the dental chair, challenges of the waiting room, perceived medical authority and the importance of continuation of care.

### *Conclusion*

In line with previous research about the importance of family-centred care, a strong relationship between parents and the whole dental team is essential for children with autism to access dental examinations and have satisfactory experience of care.

## Introduction

A recent systematic review has confirmed that children with autism have a higher risk of dental disease<sup>1</sup>. Tricyclic medications, high sucrose diets, destructive oral habits and poor self-care are contributory factors, along with facing significant difficulty in accessing preventative dental care<sup>2-5</sup>.

It is estimated that 90% of people accessing Special Care Dentistry (SCD) in the UK should be able to access treatment in a local, primary care setting<sup>6</sup>. This requires education and training of all dental care professionals to understand and respond to patients with additional needs. US studies have reported dentists' lack of autism education and training and the challenging behaviour a patient may exhibit when in a highly anxious state as factors contributing to a reluctance among some dental professionals to treat those with autism<sup>7-11</sup>.

Children with autism may become overwhelmed by unfamiliar settings and changes in routine. They may find it difficult to understand social interactions and/or communicate their needs and emotions effectively. Sensory processing disorders, which are often associated with autism, are recognised as obstructing preventative dental care<sup>12</sup>. Sensory stimuli, such as lights, touch and noise often experienced in a dental setting can be accompanied with physical withdrawal, aggressive behaviours and vocal outbursts as a child with autism becomes highly stressed<sup>13,14</sup>.

Research to date has largely been conducted from a dental professional perspective, and mostly located in North America. The studies examining strategies to assist a child with autism in overcoming challenges in attending dental services have been adapted from psychology and paediatric journals. They have identified a number of options outside of the pharmacological approaches, such as visual pedagogy, systemic desensitisation/familiarisation and behavioural guidance<sup>15</sup>. Non-pharmacological routes are favoured due to the increasing number of studies which demonstrate success using these educational principles with autistic children, and because they allow for theoretical long term adherence<sup>4,16-18</sup>. However, these non-pharmacological approaches outlined can be very time consuming and have cost implications<sup>4,15</sup>.

Parents have to utilise a variety of strategies in everyday life to help their children cope with environments and experiences most people take for granted. It is therefore understandable that a dental visit, which is a more unusual occurrence to a child reliant on set routines, may become a source of stress and anxiety for the families<sup>18</sup>.

Emphasis on the importance of including parents and advocates of autistic children when deciding on strategies has already been reported<sup>15,18</sup>. However, only one published study was identified which looked at parent experiences, specifically exploring what parents perceived to be good practice in the care of children with autism in dental settings<sup>19</sup>. Further research into family-based approaches may provide more sustainable and financially viable options to gain long term adherence with preventative dental care. The aim of this study was to gather dental experiences of parents of children with autism using primary care dentistry in the UK and explore how they feel dental services can be improved.

## **Materials and Methods**

### *Public involvement*

Public involvement in research is best practice to create meaningful partners distinct from the research participants. A working group of parents from Peninsula Cerebra Research Unit (PenCRU) Family Faculty were consulted at key stages of the research process. The PenCRU Family Faculty are a group of parents of disabled children and adults based in South West England. Six parents with children with autism offered to help with the design and conduct of this study and took part in several meetings. They helped develop the protocol, the process of recruiting families, procedures of consent and content of the study information sheets. They also helped interpret the findings of the research and write a plain language summary. Financial acknowledgement of their time contribution was offered and travel expenses were reimbursed.

### *Ethics*

The study was approved by Faculty of Health and Human Sciences ethics committee at Plymouth University (15/16-476). Potential participants received written information about the study before volunteering to take part. Informed consent was checked verbally at the start of each interview and participants provided signed consent. Any information in the transcripts that had the potential to identify participants was redacted paying attention that it didn't affect context.

### *Recruitment*

A purposive and snowballing sampling technique was adopted. As recommended by parents of the Family Faculty, a short video of the lead researcher (NT) describing the research and how participants could take part, was filmed and added to a project webpage. This video explained that NT was also a parent of a child with autism as it was felt this may encourage participation. Links to the webpage were shared on social media via the research unit's Facebook and Twitter accounts. NT also visited local autism support groups. To gather experiences from a varied sample, we checked characteristics including, socioeconomic profile of area of residence, age and diagnosis of child, as individuals registered interest in participating. The English Indices of Multiple Deprivation (IMD) 2015 (divided into national quintiles) were used as an indicator of relative deprivation of the families' areas of residence<sup>20</sup>. Look up tables were used to assign the postcode of each family to an IMD quintile. Details of the inclusion/exclusion criteria can be found in Table 1.

Recruitment ended when the perception of NT and ongoing analysis of the interviews by NT and SB were not offering any new insights or challenges to emerging themes.

### *Data collection*

Data were collected via face-to-face, semi-structured interviews which lasted up to one hour. Sixteen interviews took place in the participants' homes and one in a local café at the participant's request. Prior to recruitment, the interview topic guide was piloted separately with two parents of children with autism. Reflection on the questions being asked, was continuously undertaken throughout the data collection with small refinements and additional prompts added to elicit more information as themes emerged. The questions collected information about participant's children, including age at diagnosis and

details of their diagnosis. Questions relating to their dental experiences covered what difficulties they may have had, which were foreseen and planned for and what the dental team may have done to prevent and overcome challenges. The interviews were all audio recorded and transcribed verbatim by NT. Three of these transcripts were checked against the audio recording for accuracy by SB.

### *Data analysis*

The transcripts were imported to NVivo 11 software and analysed using a thematic framework<sup>21</sup> to identify a range of issues described. The analytical process was iterative and included periods of discussion and reflection. Two researchers (NT, SB) independently coded the first seven transcripts, reading line by line, looking both for key ideas and important issues for the parents and answers to identified research questions.

NT and SB met with the project advisory group to share the initial findings and discuss any differences between the two researchers' codes. Following this meeting, NT and SB discussed connections between codes and combined thematically similar key ideas to establish a single codebook. NT then coded the remaining interviews to this codebook whilst being open to outliers and new themes in the data. The resulting key themes and supporting quotes were shared and agreed with CM and DM. Insights and decisions made throughout the process were recorded in a teamwork journal.

### **Results**

A total of forty six individuals registered interest in the study, with forty two living in the study area being sent information about the research. Of those forty two, eighteen contacted NT to take part. A total of seventeen met the inclusion criteria (Table 1) and consented to be interviewed (Table 2). The criteria include those with a working diagnosis of autism. The working diagnosis corresponds with three girls where early detection of autism is more difficult, and to a younger male sibling where diagnosis was delayed to rule out 'copying behaviour'. There was one exclusion due to the child being outside of the age range.

Four main themes emerged from the data analysis:

1. Degree of flexibility of dental environment and team.
2. Confidence of parents to advocate on behalf of child's individual needs.
3. Continuation of service beyond the dental examination.
4. Clear referral pathway to specialist dental services

These themes were recurrent among the majority, if not all, of the parent experiences and are discussed below with illustrative quotations, followed by an illustration of best practice described by participants.

### **1.) Flexibility**

Parent experiences suggested the ability of the dental team to adjust the dental environment, where possible, and for the team to adapt to an individual child's needs and nuances was key to success.

#### *i) The dental environment*

Participating parents all reported challenges their children experience with the sensory and physical environment. The well documented sensory issues associated with autism were discussed, with some leading to potentially serious reactions from the children, including sickness, anxiety-induced irritable bowel and seizures:

*...she'll usually be hyper on the way there, very hyper...and then as soon as we get there...she will just be back and forth to the toilet...often, her name will be called and she's in the toilet...she's just very stressed. Very, very anxious, very worried about what they're going to do. [APExD4]*

However, in addition to this, there were more 'difficult to explain' sensory abreactions. These came in the form of strong responses to a person's physical appearance and/or their mood. When this line of enquiry was pursued, participants explained their children were highly attuned to the emotional environment and the body language of those around them (hyper-empathy), which led to challenging behaviours:

*...something [my child] said, "You radiate heat. When you're angry, you radiate a lot of heat."*

[APEXD32]

The physical environment was discussed during every interview, with parents often describing how the clinical nature of the setting made it a disturbing for their child with autism. Particular focus was drawn to the dental chair, as a challenge in itself to sit in, a pressure for the parents to conform to and a self-imposed measure for a successful visit:

*"Can I stand up? Do I have to sit in the chair?" And I do try and encourage him, like, "you're 8 now, why don't you sit in the chair...the dentist...is not going to do anything unless I say she can, and she'll warn you first." Um....but he won't sit in the chair. [APEXD41]*

The waiting room was often viewed with similar anxiety to the dental surgery itself; having to sit next to strangers, the busyness of the area and the time waiting for the appointment contributed to heightened anxiety detrimental to the outcome of the visit. For some parents, a great deal of energy is required in preparation which, despite best efforts, still did not mean they arrived for appointments on time. This compounded the stress as they faced possibly being turned away. Equally, if the dentist was running late, they had to make the difficult decision of whether to abandon the visit as their children became increasingly agitated.

*Because the waiting room is a whole separate thing – it's almost like having an appointment in its own right, going and sitting in the waiting room – that's a thing, and then you go and do the dentist which is another big thing. [APEXD8]*

## *ii) The Dental team*

Although additional autism training for the dental team was viewed as useful, the most successful strategies were felt to be simple changes made according to the individual child's needs; when the dental team didn't devote sufficient time to explaining procedures to their children, for example, the

outcome of the visit was typically unsuccessful. Equally, the onus wasn't placed wholly on the dentist; the whole dental team had a part to play in creating a friendly environment.

*There's quite a snotty receptionist there. I don't think she's at all child-friendly to be fair.*

*...the slightest squeak that [my child] makes and she's on the phone and she's like, "oh. Um.*

*I'm sorry. I can hardly hear you, we've got some children in here, and they're being a bit naughty."* [APExD26]

Communication during the examination needed to be unambiguous and giving children time to process and understand information was vital. Building a relationship with the children that modelled good practice for social interactions was seen as important and, conversely, lack of rapport was an influential factor in negative experiences.

*[My child] has a need to know...it's no good them just saying, "This is what we're going to do," because [my child] will think of a question that they haven't explained.* [APExD4]

*So, we had to wait nine months and by the time we did get to see someone, it was someone totally different again so for the last three years, they've seen, I'd say about, four dentists, five dentists and it's changed nearly every time we've gone.* [APExD42]

## **2) Confidence of the parent**

For a successful visit, parents needed to feel confident to advocate for their children and ask for environmental and behavioural modifications. Two aspects seemed to affect parents' confidence: giving medical authority wholly to the dentist, and the parents' own experiences of dentistry.

### *i) Medical authority*

There was an assumed authority that the medical expertise of the dentist qualified them to understand what was best for their child. There were also reported occasions when the parents didn't feel confident in challenging the dentist when issues arose, for example, when the examination unexpectedly turned into treatment and the parent subsequently regretted their decision not to intervene.



*I just told them that she was autistic really. I mean, to be honest, they don't really, they just go 'oh, ok'. You assume that they understand what that entails. [APExD33]*

*...and perhaps I should have said more, but, how much could, how much could the dentist, I suppose my theory, how much could the dentist have done when they've already got the stuff in her mouth and were trying to do it...I just had to ride it out and cope best I could with coping. [APExD6]*

Parents were acutely aware of the need for good oral health for their children who often had severe aversions to toothpaste, toothbrushing and had poor diets. In some cases, due to the broader challenges these families face, oral health became a low priority. Some parents, after conversations with the dental team, felt unfairly judged due to the lack of understanding about the difficulties often associated with carrying out basic self-care, the limited diets and fixations to objects children with autism can have.

*We faced a lot of 'what does he eat?' and I'm like...sometimes, all I can get him to drink is milkshake. Like, I don't want to give him milkshake, I know milkshake is noooo good for him, but...I need him to have SOMETHING...and...he was having a bottle and how hard it is to take a bottle away from a child that is not wanting to give it up?... I don't want him to have a bottle, seriously, but I can't just bin his bottles! That's not an option for us. [APExD7]*

## *ii) Parent experience*

Parents who had suffered negative dental experiences themselves as a child seemed determined to provide positive dental visits for their children. All of the parents reported taking their children for dental examinations from an early age and therefore before an autism diagnosis.

*...when we started doing dentists, we didn't know anything about his autism. Um...that's just the way it was because I had an 18 month old and 9 month old...so it's always been stressful. I have to grin and bear it and have a glass of wine at the end of it! [APExD25]*

Rather than using strategies taught by autism services, parents developed their own instinctive strategies based on their child's needs to prepare their children for a dental examination. Parents expressed

the importance of the dental team listening to their child's individual needs in order to ensure the best from the appointment, rather than working on a taught understanding of autism.

*It's no disrespect to the dentist...they've done their training...so they've done everything they need to learn their field, but as an individual, obviously the carer, parent, knows best for that individual and they need to listen to what's being said and then, even though, you know, it's great for the dentist if the child sits in the chair and it leans back and it's all brilliant, if they're not going to sit there then you need to move to them and obviously, and it does make things harder. [APExD26]*

### **3) Continuation of service**

A number of issues were raised about the medical history questionnaires and what happened to the information provided by parents. Some reported a lack of confidence in whether the information was being utilised by the dental team or if the information was being stored correctly for continuity of care, should the dentist leave or change, which was often the case.

*...you go and every time I've had to repeatedly fill out forms and every time I have put autism and not one person, which is a shame really, has...and when you've changed dentist, talked about it or even said, "oh, I see they've got autism. Is there anything I should know?" [APExD23]*

Parents felt effective communication occurring beyond the dental examination significantly improved the chances of a successful visit. Many parents reported the negative impact dental examinations had on them as a family; both the anxiety and stress before, during and after the dental visits. They also felt it important for the dental team to be aware of the possible impact unsuccessful visits have on them as a family after the visit. Stress reportedly lasting for long periods afterwards, manifesting in violence at home, children self-harming and, in some cases, the child completely refusing to return to any dental service. How this negatively influenced siblings whom may or may not also have autism spectrum conditions was a grave concern, therefore parents felt additional pressure to achieve a successful dental visit so siblings didn't develop fears based on witnessing difficulties that were experienced.

*“It’s the aftermath. The older one, uh, takes it out on me. Can get very violent. Um...and he’s bigger than me now so, it can hurt quite a lot. Um...and he gets very aggressive, and he gets aggressive to his brother and his brother gets aggressive as well and so that will then carry on for the rest of the night. Basically, he’s got no ability of shutting it off and you know you’re going to have a really bad night. The younger one, he cries. Um...shakes and um, sometimes can bring on his seizures.” [APExD42]*

Stress was alleviated in instances where the dental team were involved in helping the families prepare by providing information on what to expect from their visit, by collecting information about their child in order to make environmental adjustments and keeping contemporaneous notes so parents didn’t have to repeat the same information at every visit.

#### **4) *Clear referral pathway to specialist dental services***

In one particular instance, where all three of the above themes were described positively, the child refused to attend the dentist for an examination. The child had been visiting the same dentist for most of her life, with outstanding communication between the mother and dentist but found it increasingly difficult to cope with visits. This manifested itself in extreme self-harm and/or destructive behaviour whenever the parent tried to take her to the dentist. The child has always found explaining her severe reluctance to dental and other health services very challenging and has since been diagnosed with Pathological Demand Avoidance.

Confusion over the specialist dental services available to children in similar difficulty, and how to refer was reported by a number of parents with the parents either researching and informing the dentists themselves or experiencing a delay in accessing appropriate dental care because of barriers to the referral process.

*...we actually then had the school nurse [...] and it was her that said go back to the dentist and ask him to refer you to the Access Centre which I did and then the general practitioner, manager,*

*whatever you call it, said to me, “well, I’m not doing that,” she said, “because we can’t afford to lose our patients,” and it was basically money-based which was totally the wrong answer. So, I went back and told the school nurse who said, “right, I’ll do it.” [APExD16]*

### **Best practice**

Clear and open communication seemed to be the focal point of all discussions, with both parents needing to feel confident to advocate for their children and the dental team being flexible in response; a collaborative partnership that works in the best interest of all.

*“Well, I suppose it’s more of ‘we’, as parents need to actually give them what works for our child or what our child – because with the autism and Asperger’s, they’re all so different – to have a blanket, ‘well this is what you need to do’ I suppose is quite hard to do, but I mean, maybe it’s more, the practice is saying ‘well let us know what we can do for you – what do you think is going to work for you?’” [APExD25]*

A working example of this was a parent who approached her dentist and asked if she could take photographs to create a social story for her child. In addition to this, the dentist gave clear instructions on what to expect on the first visit and did not deviate from what was agreed. The dentist learned the child had a fascination with washing machines and as there was a washing machine at the practice, it became a motivator for the child to have his dental examination and then be allowed to look at the washing machine. The whole dental team were involved and the receptionists would take the child to see the washing machine if it appeared a wait for the dentist was going to occur.

*I don’t think she had any dealings with autism before that. I’m not sure she has now, you know, since. But I just think it was her open attitude and the fact that we said, ‘look, is this...you know, we want to do this, is this ok?’ and she was like, ‘yeah, absolutely.’ So, it was her, completely her attitude, you know. [APExD15]*

This demonstrates the confidence of the parent to communicate her child's needs, the flexibility of the dentist to adapt and the continuation of service when the whole dental team became involved to enable the child to look forward and enjoy his dental visits.

However, even when these three positive factors present, needing to have a very clear understanding of where and when to refer a child to a specialist dental service should issues arise, links in the fourth theme to create 'best practice'.

A preliminary conceptual model illuminating the linked nature of the key themes is demonstrated in Figure 1.

## **Discussion**

Although the findings of this study in part accords with previous studies highlighting the difficulties children with autism can experience when attending for a dental visit, this study is one of very few that looks directly at parent experiences of taking children with autism for a dental examination. It offered similar findings to the one other identified study found which explored parents' perception of good dental practice and barriers parents of children with autism experience<sup>19</sup> being the value of effective communication and the willingness of the dental team to listen and adapt to a child's individual needs.

This study adds weight to those findings by offering novel understandings of other factors that also play a role such as, the perceived medical authority of the dentist affecting parent confidence and their ability to advocate for their child. This is an important aspect of effective communication which dentists may need to consider when attempting a family-centred approach. Accepting and verbalising the limitations of their autism knowledge and actively seeking counsel from parents may positively influence parent confidence to advocate for their child, which could extend to other health services as well. In addition, confusion over referral to specialist dental services, with a lack of knowledge being highlighted by both dental professionals and parents, damaged parent confidence.

Due to the complex organisation of community and specialist dental services which differ greatly from area to area in the UK, it is unclear whether a clear referral pathway to specialist services exist and whether it is the dentist's or specialist service's responsibility to make their whereabouts and referral protocol known.

A surprising finding to this study was the lack of taught coping strategies that parents might use to assist their children when accessing dental services. The options outside of the pharmacological approaches identified in the literature, such as visual pedagogy and desensitisation, which are taught through autism services and professionals<sup>4,15-18</sup>, were mentioned by a small number of parents but were not viewed as integral to the success of a visit. This is because the needs of an autistic child often change and what may have worked at the dental visit six months previously, may no longer be relevant. Children may also be attending dental practices for several years prior to a formal diagnosis, as was the case for many of the children in this study. Therefore, having an acceptance of a child's needs, an understanding that extreme anxieties may go beyond those of a neurotypical child and flexibility to make changes to adapt to the child's needs outweigh the requirement for in depth autism knowledge.

Parents identified many salient issues that may not have been previously acknowledged in the literature regarding the challenges families face when attending a dental appointment and the impact when relationships are unsuccessful. These included the importance of the dental team being aware of how highly attuned an autistic child can be to the emotional environment which was described as hyper-empathy. The non-verbal body language of the dental team may be of equal importance to a child with autism alongside the importance of 'modelling' good social behaviour by having a happy and polite demeanour. Parents felt the dental team having an understanding of the possible impact of not having a family-centred, autism-friendly approach would be vital in helping the dental team understand the challenges of autism and be more willing to adapt to their child's needs. In particular, in relation to how breakdowns in relationship between the dental team and parents impacted critically on the families, with violence, self-harm, children

refusing to attend, deterioration in parent confidence of dental services and delays in care due to refusal of the dental team to treat the child.

It could be argued that time pressures and performance targets, which NHS practices have to adhere to, may affect the ability of a dental practice to be able to provide additional support to these families. However, as the participants in this study reported collectively, much of the preparation occurs prior to appointments by the families. There was some ambiguity over what 'examinations' and 'treatment' actually meant with examinations often turning into a procedure that the family may not have been expecting. Continuation of service could include conversations prior to the appointment in order to plan the appointment and discuss any potential problems to alleviate stress and anxiety over the 'unknown' factors, for both parents and their children. This includes not deviating on any appointment plans that may have been agreed and discussed with the children and parents. Continuation of service that goes beyond just the dental examination could be accomplished by utilising the whole dental team; receptionists, practice managers, dental nursing assistants, and other dental care professionals. Ensuring contemporaneous notes for continuity of care would aid transition between dental providers and provide post examination information for the parents should they wish to access it. Parents argued the need for a better alerting system on computer records so the information about their child is highlighted to any member of the dental team reading their child's notes. This could reduce the frequency of repeated discussions about their child's needs as parents often found this time-consuming, energy-sapping and difficult in front of their children, who may not always be aware of their diagnosis.

Autism awareness was discussed at every interview and it was agreed by all that some understanding of autistic spectrum conditions would be beneficial for the whole dental team, particularly in relation to advising about oral health and diet. A perception of being unfairly judged affected the confidence of some parents and consequently how they interacted with the dental team. Many of the children have very limited diets and severe aversions to toothpaste and toothbrushing. Alternative methods of fluoride

delivery over and above the usual means of toothpaste must be a discussion with any family dealing with a child that may or may not yet be diagnosed with an autistic spectrum condition<sup>22</sup>.

Parents that had created good relationships with their dental providers tended to be from health or education working backgrounds. However, even with the best of intentions and being a confident and proficient communicator, without the reciprocal flexibility from the dental team, dental visits were often not successful and unfortunate breakdowns in relationships and confidence in public services occurred leaving some parents feeling desperate about the situation and the future of their children's dental care.

The small sample, lack of cultural diversity in South West England and the fact that all the respondents that took part were mothers limits the applicability of these findings. While the families who took part in this study lived in varied areas of socio-economic deprivation (as measured by IMD), engaging with families in more diverse areas may offer further insights as to whether differing social, educational and economical backgrounds alter the conceptual model

The children, whose experiences are discussed in this paper, had a range of comorbidities (Table 2). As the parent experience shows that each child will be affected individually, it is suggested that the initial conceptual model is still helpful but further research could explore whether comorbidities profoundly affect the parent experience. In addition, future research may also want to explore fathers' and other carers' experiences, dental providers' attitudes to treating patients on the autistic spectrum and how dentists may be able to improve parent confidence in advocating for their children's dental care. It may also offer new insights by increasing the age beyond 13 years old and interviewing subjects with autism directly.

The lead researcher, NT as a dental care professional and a mother to a child with autism helped build rapport with parents. Any potential for bias was regularly reflected on in discussions with the wider team and through the involvement of the Family Faculty as an advisory group.

## **Conclusion**



Parents are the experts and advocates for their children with autism in everyday life so will likely have answers to many potential issues that may arise from a visit to the dentist. It is not only important to take guidance from primary carers of children with autism, but it is also vital to have an understanding there may be a barrier to their ability to advocate for their child due to a perceived medical authority. Having an awareness of 'hyper-empathy' that a child with autism may experience which coincides with positive social encounters being modelled by those in authority, are both significant factors for the whole dental team to consider when a child with autism accesses primary dental care.

The conceptual model which highlights the importance of flexibility of the dental team and environment, the confidence of the parents advocating for their child and the importance of the continuation of service beyond the dental examination all being held together by effective communication, is believed by parents to be key to improving access to primary care dental services for their children with autism. In addition, having clear referral pathways to specialist dental services to avoid any delay and distress for families would provide a framework for a 'best practice' protocol for autism families attending primary care dental services.

### **Conflicts of interest**

The authors declare no conflict of interest. The funders, The Oral & Dental Research Trust, had no input into the design or analysis of this research.

### **Bullet points – what this paper adds**

- **Provides novel insights into the experiences of parents of children with autism when attending primary care dental services in UK.**
- **Explores novel concepts, such as 'hyper-empathy' and perceived medical authority experienced by families of children with autism**
- **Adds weight to previous studies which highlights the need for a family-centred approach when treating children with autism.**

## **Bullet points – why is this paper important for paediatric dentists**

- **Gives valuable new insight into difficulties autism families face and the impact to families when communication is not effective**
- **Offers considerations to dental service providers who may encounter families of children with autism, including promoting parent's confidence in advocating for their child and continuation of service outside of the usual dental examination**
- **Provides recommendations on how to improve primary care dental services for children with autism**

<sup>1</sup>da Silva SN, Gimenez T, Souza RC, Mello-Moura ACV, Raggio DP, Morimoto S, et al. 2016. Oral health status of children and young adults with autism spectrum disorders: systematic review and meta-analysis. *International Journal of Paediatric Dentistry*.

<sup>2</sup>DeMattei R, Cuvo A, Maurizio S. 2007. Oral assessment of children with an autism spectrum disorder. *Journal Dental Hygiene*, 81:65.

<sup>3</sup>Ebtissam Z Murshid, 2014. Diet, Oral Hygiene Practices and Dental Health in Autistic Children in Riyadh, Saudi Arabia. *OHDM*. 13(1) 91-96

<sup>4</sup>Mohamed Abdullah JABER, 2010. Dental caries experience, oral health status and treatment needs of dental patients with autism, *Journal Applied Oral Science*, 19(3), 212-7

<sup>5</sup>Rennan Y Du et al, 2015. Oral health among preschool children with autism spectrum disorders: A case control study, *Autism*, 1-6

<sup>6</sup>Kopycka-Kedzierwaski DT, Auinger P. 2008. Dental needs and status of autistic children: results from the National Survey of Children's Health. *Pediatric Dentistry*; 30, 54-8.

<sup>7</sup>D Faulks et al, 2012. The value of education in special care dentistry as a means of reducing inequalities in oral health. *European Journal of Dental Education*, 16(4), 195-201.

<sup>8</sup>Taryn N. Weil BS et al, 2011. Treating patients with Autistic Spectrum Disorder - SCDA members' attitudes and behavior. *Special Care Dentistry*, 31(1), 8-11.

<sup>9</sup>Taryn N. Weil et al, 2010. Dental Education and Dentists' Attitudes and Behavior Concerning Patients with Autism. *Journal of Dental Education*, 74(12), 1294-1307.

- <sup>10</sup>Konstantina Delli et al, 2013. Management of children with autistic spectrum disorder in the dental setting: Concerns, behavioural approaches and recommendations. *Medicina Oral Patologia Oral y Cirugia Bucal*, 1;18(6), e862-8.
- <sup>11</sup>Sinead Lydon et al, 2014. A Systemic Review of the Treatment of Fears and Phobias Among Children with Autistic Spectrum Disorders. *Review Journal of Autism and Developmental Disorders*, 2(2), 141-154.
- <sup>12</sup>Cheen Y. Loo et al, 2009. Behaviour guidance in the dental treatment of patients with autistic spectrum disorder. *International Journal of Paediatric Dentistry*, 19, 390-398.
- <sup>13</sup>Leah L. Stein MA OTR/L et al, 2011. Oral care and sensory sensitivities in children with autism spectrum disorders, *Specialist Dental Care*, 31(3) 102-110
- <sup>14</sup>Ayres AJ. 1964. Tactile functions: their relation to hyperactive and perceptual motor behavior. *Am J Occup Ther* (18) 6-11.
- <sup>15</sup>Miller-Kuhaneck H. Going to the dentist. Available at: <http://www.spdfoundation.net/library/dentist.html>
- <sup>16</sup>Travis M Nelson DDS, MSD, MPH et al, 2015. Educational and therapeutic behavioural approaches to providing dental care for patients with Autism Spectrum Disorder, *Special Care Dentist*, 35(3) 105-113
- <sup>17</sup>Ichijiro Morisaki DDS PhD et al, 2008. Behaviour guidance in dentistry for patients with autistic spectrum disorder using a structured visual guide, *Journal of Disability and Oral Health* 9(3) 136-140
- <sup>18</sup>Lorena M Orellana et al, 2014. Training Adults and Children with an Autism Spectrum Disorder to be Compliant with a Clinical Dental Assessment using TEACCH-Based Approach, *J Autism Dev Discord*, 44, 776-785
- <sup>19</sup>Brown, J., et al. (2014). Dental services for children with autism spectrum disorder. *Learning Disability Practice* 17(3): 20-25.
- <sup>20</sup>English indices of deprivation 2015. Department for Communities and Local Government. 2015. Available at <https://www.gov.uk/government/statistics/english-indices-of-deprivation-2015>
- <sup>21</sup>Ritchie J, Spencer L 1994 Qualitative data analysis for applied policy research. In Bryman A, Burgess RG (eds) *Analyzing Qualitative Data*, London, Routledge
- <sup>22</sup>Delivering better oral health: an evidence-based toolkit for prevention. Department of Health. 2017. Available at [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/605266/Delivering\\_better\\_oral\\_health.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/605266/Delivering_better_oral_health.pdf)

Table 1. Inclusion Criteria

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> <li>▪ Parent carers of: <ul style="list-style-type: none"> <li>○ Child who has confirmed or working diagnosis of autism, including Asperger’s syndrome, PDD-NOS, Regressive, PDA, Rett Syndrome</li> <li>○ Male and female children</li> <li>○ Aged 4 – 13 years old</li> <li>○ Co-existing conditions such as Down’s Syndrome, Epilepsy, ADHD, learning disability are included</li> <li>○ Has had at least one visit to a primary care dentist in the past two years.</li> <li>○ Live in Somerset or Devon, including Plymouth or Torbay (UK)</li> <li>○ Be an English speaker</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>▪ Parent carers of: <ul style="list-style-type: none"> <li>○ Child aged 13 years and above</li> <li>○ Child can only access dental care under sedation/general anaesthetic/restraints</li> <li>○ Child who has never accessed any dental services</li> </ul> </li> </ul>

Table 2. Sample Characteristics

Participation ID	Age of Parent	IMD Score (quintile)	Age of Child	Gender of child	Age of Diagnosis	Comorbidities	Schooling
APExD2	40-49	11.19 (2 <sup>nd</sup> )	5	M	3	None reported	Special
APExD3	40-49	11.19 (2 <sup>nd</sup> )	5	M	3	None reported	Mainstream
APExD4	40-49	7.35 (1 <sup>st</sup> )	9	F	9	AD	Mainstream
APExD6	30-39	14.89 (3 <sup>rd</sup> )	9	F	W	APD/tinnitus/ microphonia/ hyperacusis/SPD	Mainstream
APExD7	20-29	14.89 (3 <sup>rd</sup> )	5	M	3	None reported	Special
APExD8	30-39	10.60 (2 <sup>nd</sup> )	6	M	3	SPD/sleep disorder	Mainstream
APExD12	30-39	12.18 (2 <sup>nd</sup> )	12 & 9	M & M	7 & W	None reported	Mainstream

APExD15	50+	12.14 (2 <sup>nd</sup> )	11	M	3	APD	Special
APExD16	40-49	14.91 (3 <sup>rd</sup> )	11	M	7	NPD*/ADHD*	Mainstream
APExD23	40-49	21.11 (3 <sup>rd</sup> )	11 & 13	M & M	8 & 2	None reported	Mainstream & Out of school
APExD25	40-49	17.32 (3 <sup>rd</sup> )	9	M	5	None reported	Mainstream
APExD26	40-49	6.90 (1 <sup>st</sup> )	7	M	2	Sleep disorder	Special
APExD27	40-49	14.89 (3 <sup>rd</sup> )	12	F	12	None reported	Home School
APExD32	40-49	20.95 (3 <sup>rd</sup> )	11	M	11	SPD/APD/PDA	Special
APExD33	40-49	10.56 (2 <sup>nd</sup> )	13	F	11	PDA/APD/AD	Mainstream
APExD41	30-39	9.15 (2 <sup>nd</sup> )	8	M	8	None reported	Mainstream
APExD42	40-49	17.10 (3 <sup>rd</sup> )	10 & 13	M & M	9 & 5	ADHD & paradoxical benign vertigo	Mainstream

Key: AD = Anxiety Disorder. APD = Auditory Processing Disorder. SPD = Sensory Processing Disorder. NPD = Narcissistic Personality Disorder. ADHD = Attention Deficit Hyperactivity Disorder. PDA = Pathological Demand Avoidance.

\* Suspected, awaiting diagnosis.

Table 3. Additional data

1. Flexibility	i. The dental environment	<p>Not necessarily helpful – he didn't like the actual face of the assistant. I thought she was lovely, but it wasn't his, his...apparently, she had a flat face! I don't know what that means! But she had one and he didn't like it! [APExD16]</p> <p>[My child] is very aware of how I'm feeling, although they say that autistic children find that hard, I don't think they do. I think they have a hard time explaining what they know in regards to emotions. [APExD7]</p> <p>Refused to open his mouth, didn't like the smells, didn't like the chair, didn't like it going up, didn't like it going down, didn't like the little pulley thing that you spit in, just absolutely, was just utter hysteria. [APExD16]</p> <p>Um...in the waiting area, he gets quite anxious. "Can we go in yet? Can we go in yet?" and it's like, "well, no, we can't go in till we're called." And he's very repetitive so he'll go, "can we go in yet?" and people look at me and think, you know, and they laugh. It's like, it's not funny, it's just the way he is. [APExD41]</p>
----------------	---------------------------	--

		<p><i>I think I was ten minutes late once and I went there and really apologised, and I was stressed and they said, “Oh, I’ll go and check with the dentist”, and I could see he was in the room, and she came out and said he wouldn’t see them and um...I complained...and then he did. But he was, you could tell he was fed up and I thought, “actually, I wish...I don’t want you to do this now...” but I knew that if I didn’t do it then, I’ve only got to go through it all another day! [APExD23]</i></p>
	<p><i>ii. The dental team</i></p>	<p><i>I think, in fairness, it’s like with any child, it’s just actually if you know how your child operates or how, if your child responds to this, but not that, or vice versa, taking that information is going to make it easier for them? But, you almost get an impression of, “yeah, but we just need to look at his teeth.” [APExD12]</i></p> <p><i>Umm...but I have sort of explained to the boys what is going on, what could happen. Um...didn’t go down too well; me eldest had to have a filling and it was suddenly thrown upon him and I said, “woah, you’ve got to tell him what you’re doing. You can’t just do it! You’ve got to explain what you’re doing the whole time you’re doing it because this is the only way he’s going to cope!” [APExD42]</i></p> <p><i>She needed to slow down. That was her fundamental thing which to me, makes it all so, “right, in here, do that. Right next!” You’re like next on the processor but actually, [my child] couldn’t do it like that. She needed to be much slower and, and prepared. [APExD27]</i></p> <p><i>Again, the dental nurses never seem to have a role, they just...it’s like a non-verbal person in a mask passing things – I find it bizarre. And um...it’s just that environment – I find it a bit bizarre. [APExD23]</i></p>
<p><i>2. Confidence of parent</i></p>	<p><i>i. Medical authority</i></p>	<p><i>I just told them that she was autistic really. I mean, to be honest, they don’t really, they just go, “oh, ok.” Um, you assume that they understand what that entails. [...] you tell a dentist, “She’s autistic,” that they’ll know, but you know. You don’t know really do you? [APExD33]</i></p> <p><i>I think they just looked at me like, “help!” I think they looked at me to have all the answers and uh I think it’s really difficult isn’t it, because at that point in time I didn’t have all the answers...[APExD2]</i></p> <p><i>...perhaps I should have said more, but, how much could, how much could the dentist, I suppose my theory, how much could the dentist have done when they’ve already got the stuff in her mouth and were trying to do it. I think that, at that point, I think I just had to ride it out and cope best I could with coping. [APExD6]</i></p> <p><i>I think sometimes dentists put the pressure on the parents too much as in, you know, “it’s your job to make sure they brush their teeth.” Yes but, you know, if you’ve got a child that uh violently hits you because you’re trying to do it, you, after a while you tend not to um...you tend to not bother. [APExD32]</i></p>
	<p><i>ii. Parent experience</i></p>	<p><i>...it’s quite, upsetting really, to think that they are, scared of the dentist [...] Despite everything that I have done, because I hated it. I didn’t go back when I was 18 and I was able to take charge of myself, I didn’t go</i></p>

		<p><i>for ten years because I refused, because of the experiences I'd had when I was younger. [APExD42]</i></p> <p><i>So, it's fallen back on me but you know, I always avoided taking her myself because I didn't want to pass on my own anxieties and that was all fine when it was just looking with a mirror and counting. Um....but no, I'm not, I'm not a big fan. I'm not a big fan and I'm aware that even, you know, even with the best intentions, I'm sure my own...nerves...must, even though, I know what I need to do, they must still...pass on, mustn't they? [APExD4]</i></p> <p><i>I think it's down to the dentist. Like the high street dentist. I think he's really good...because I'm scared of the dentist and he gets me in there *laughs*... [APExD7]</i></p>
<p><i>3. Continuation of service</i></p>		<p><i>...you go and every time I've had to repeatedly fill out forms and every time I have put autism and not one person, which is a shame really, has...and when you've changed dentist, talked about it or even said, "oh, I see they've got autism. Is there anything I should know?" [APExD23]</i></p> <p><i>I do remember at the time, they scanned it in, to his notes on the computer so it would flag up when we first got there, which would have been a positive, if it had of worked, obviously. [APExD16]</i></p> <p><i>I mean I don't know what the notes were like so I don't know how much of her fears were recorded and I don't know whether that might have been a factor. That, if she had been able to be more prepared by what it said, than that might be good. Because that's obviously my other worry is that we're now totally in the hands of one person, even though we're not seeing him at the moment, but...you know, what if he does move away again and I can't stalk him, um...or what if he doesn't do it anymore, so I think the hand over, the continue...wha...was...yes, the continuation of care, I think will be really important. [APExD27]</i></p>
<p><i>Clear referral pathways to specialist dental services</i></p>		<p><i>So, I said, "there's nowhere...you sure there isn't anywhere?" and eventually, they were like, "oh actually, yeah, we found out there is one," and no waiting list. Literally letter went in and we were seen within two weeks. So, it's been really good. But, it's because I knew. Not because they knew. In all honesty. It wasn't led by them. [APExD12]</i></p> <p><i>Um...we're in the middle of trying to get a referral to the ASD clinic but no one seems to actually know the address to refer to. [APExD6]</i></p>
<p><i>Examples of positive experiences</i></p>		<p><i>So, he wanted to talk about this whole extraction thing and going to see an orthodontist so he just rang me one time and had a chat about it and talked about the referral and how he would make that work. So, um...yeah, he was very good at, very good at communicating. [APExD27]</i></p> <p><i>Literally, just talking to him. Showing him, Explaining to him. Going through it. Just to show him, yeah, how it's going to be and make sure he was settled and happy. Which was amazing. And then she came out with him, to make his next appointment, and...well we just waiting to make the appointment, I was dealing with some of that, she was talking to him just about the posters, of like, just literally building up a really good rapport with him. [APExD12]</i></p>

	<p><i>His brother, he's got an older brother, so he would watch him having his check-ups done and me having mine done um so we've had several visits of, of that and then we had a couple of check-ups where he would sit um on the floor, the dentist would get down on the floor beside him... [APExD3]</i></p> <p><i>They had two different colour drinks rinse and spit, and she was, "which one do you want? The pink or the green?" and very much more interactive, very much he was leading if you like. [APExD16]</i></p>
--	---

\*Quotes are followed by participant identification codes. For all extracts, square brackets containing an ellipsis [ ... ] indicates short sections of omitted speech; square brackets containing text indicate explanation added during transcribing or analysis, usually for anonymity.

Figure 1. A conceptual model illuminating the linked nature of the key themes

