Dental services for children with autism spectrum disorder

Jeremy Brown and colleagues describe a pilot study to assess how parents perceive good practice and barriers to care

Abstract

Aim To identify what parents perceive to be good practice in the care of children with autism in dental settings and to highlight difficulties in accessing dental services.

Method An online questionnaire survey with open and closed questions followed by a series of in-depth semi-structured interviews. Mixed-method quantitative and thematic analyses were performed.

Results Of 19 participants, 13 reported that they had been able to access dental services but 12 experienced difficulties related to their children’s condition when visiting the dentist.

Conclusion The approach and communication skills of dental staff, and their willingness and ability to adapt their practices for children with autism, are all important.

Keywords Autism spectrum disorder, children, communication

IN JANUARY 2012, the authors organised a scoping exercise with selected delegates who had attended an annual autism conference organised by Edge Hill University and Belle Vue House Assessment Centre, in Ormskirk, Lancashire. The aim of this exercise was to identify issues that could be developed into research projects with outcomes that would inform people with autism spectrum disorder (ASD) their carers, and professionals.

The authors facilitated the debate with people with ASD, parents, carers, health and education professionals, representatives of charities and academics. Discussions centred on difficulties associated with accessing health services and, to pursue these perceived difficulties, the authors focused their research investigations on dentistry.

Children and their families are encouraged to visit dental surgeries regularly and dentists may encounter difficulties relating to service users with ASD before any other health professionals. This is exemplified by Berman (2010), who argues that dentists are often the first healthcare professionals to encounter young clients with sensory sensitivities and behavioural characteristics.

Visits to dentists can create anxiety even before examinations or treatments have taken place and, for those on the autistic spectrum, these anxieties can be intensified by additional factors, such as sensory processing dysfunction, communication limitations and inflexibility or rigidity.

The aims of the authors’ project were to identify:

- What parents perceive to be good practice in supporting children with autism in dental settings.
- The barriers faced by parents who support children with autism to access dental services.
- ASD can have a significant effect on ability to function. The triad of impairments associated with ASD, namely difficulties with social communication, social interaction and social imagination, create problems for the people concerned, especially when they are combined with sensory processing deficits.

This was recognised by Venkat et al (2012), who said: ‘For physicians who encounter patients with an ASD, the combination of impaired social interactions, difficulties with communication and stereotyped behaviours creates an additional barrier to diagnosis and treatment of these individuals.

‘Careful preparation of the examination environment, direct engagement of carers and
In the UK, Barry et al (2013) describe one study undertaken in the north of England, which revealed the same problems. Hernandez and Ikanda’s (2011) literature analysis concludes that future research is needed to remedy the lack of an evidence base to inform dentists making professional judgements about altering their practice to address the behavioural characteristics of children with ASD. These concerns are shared by Kuhaneck and Chisholm (2012), who suggest that some dental practitioners are unaware of the difficulties with sensory processing common to clients with ASD.

Kuhaneck and Chisholm’s (2012) and Stein et al’s (2013) US-based studies support that of Green and Flanagan (2008), reinforcing the significance of sensory processing problems relating to oral care in the home and in the dental surgery.

Both studies conclude that strategies are needed to alter practitioner interventions and the sensory characteristics of the dental environment, to reduce children’s sensitivities.

In Stein et al’s (2012b) mixed-methods study of sensory-related aspects of oral care reported by parents at home and at the dental surgery, a comparison is made between children with ASD and their typically developing peers. Results indicate that significantly more parents of children with ASD report difficulties with sensory-related oral care.

Many dentists in the US say that their undergraduate training did not prepare them for working with service users with ASD, although those who adopt behaviour management strategies record better treatment outcomes (Weil and Inglehart 2010). Organisations responsible for dental education in the US have been called on by Weil and Inglehart (2010) to reconsider how they prepare dental graduates for the treatment of clients with ASD.

In the UK, the General Dental Council (2012) states that dental students ‘should be able to recognise and take account of the needs of different patient groups, including children, adults, older people, and those with special care requirements. Appropriate communication and good interpersonal skills are crucial to being an effective registrant’.

In theory, children with an ASD diagnosis will access special needs dentistry. However, many families are caring for children who have not had a formal ASD diagnosis. A survey published by the National Autistic Society (Bancroft et al 2012) points out that more than one in three respondents had to wait for three years or more for a diagnosis, after initially raising concerns.

**Research project**

**Methodology**
To ensure parents’ experiences would be explored comprehensively (Creswell 2009, Robson 2011), the authors’ proposed a mixed-methods study split into two phases.

In the first, an online questionnaire with open and closed questions would be sent to potential participants and, in the second, respondents would be asked to take part in semi-structured interviews based on responses to the questionnaires. The proposed study was scrutinised and approved by the research ethics committee in accordance with the university’s guidelines.

All 206 parents of children with ASD who had attended the autism conference at Edge Hill University over the past seven years were sent emails that introduced the authors, described the purposes of their study and invited the recipients to participate.

Interest was expressed by 29 of the parents and they were sent a link to the online questionnaire and an invitation to participate in the interviews. The questions have been adapted for Box 1.

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**Box 1** **Questions for parents of a child with autism spectrum disorder**

- How old is your child with autism spectrum disorder (ASD)?
- Is your child male or female?
- Does your child experience sensory processing difficulties?
- Has your child been diagnosed with autism, ASD or Asperger syndrome?
- Is your child verbal or non-verbal?
- How would you describe the level of your child’s learning difficulties?
- How would you describe your child’s level of communication impairment?
- Does your child have another diagnosed condition?
  - If your child has another diagnosed condition, what is it?
- Do you face barriers when your child must access dental services?
- Can your child access special needs dental services?
- How often does your child visit the dentist?
  - If your child has never attended a dental appointment, why not?
- Have you visited mainstream, special needs or both kinds of dental service?
- Are there differences between mainstream and special needs dental services?
  - If you have experienced such differences, what are they?
- Have you experienced difficulties when visiting a dentist?
  - If you have, were they associated with your child’s ASD?
- What were these difficulties?
- What positive experiences of dental services have you had?
- What would make access to dental services easier for your child?
- What skills and characteristics should dentists need to deal with your child’s ASD?
- How can dental services help your child?
Nineteen of the 206 parents completed the online questionnaires and it was assumed that, by doing so, they were giving their informed consent to participation in the project. Answers to open questions were analysed thematically (Ritchie and Lewis 2003), while answers to closed questions were analysed descriptively using the SPSS Statistics software package. Four of the 19 parents who completed questionnaires also returned by post signed forms giving their consent to take part in semi-structured interviews to discuss some of the issues raised in the questionnaire.

These interviews, which took no longer than 30 minutes each, were conducted by telephone at times convenient to the interviewees. They were recorded, and the results were transcribed verbatim and analysed with reference to Ritchie and Lewis’s (2003) thematic framework.

To protect the confidentiality of participants, all names or identifiable characteristics were removed from questionnaire data and interview transcripts, and all data were stored according to the Data Protection Act 1998.

Each of the three authors then independently analysed qualitative data from the 19 completed questionnaires and four interview transcripts to test the credibility of the findings, before meeting to discuss their findings. Having found no variations in their analyses, the authors organised their findings into themes, and then defined and re-defined theme descriptors until all data had been fully represented (Miles and Huberman 1994).

**Results** The data reported by parents concerned 19 children: five aged between five and seven years, six aged between eight and 11 years, seven aged between 12 and 15 years, and one aged between 17 and 21 years. Thirteen of the children are male and six are female.

Eleven children were said to have average or above average learning abilities, five mild or moderate learning difficulties and three significant learning difficulties.

Seventeen children were said to be verbal and two non-verbal. Three of the former group of children had no communication impairments, which is perplexing given that communication deficit is an important indicator of ASD. The children's communication impairments were said to be mild in nine children, moderate in three children and significant in three children.

Five of the 19 parents claimed that their children had also been diagnosed with other conditions, including attention deficit hyperactivity disorder and dyspraxia.

All 19 children visited dental services regularly. Fourteen had been taken to mainstream dental services only, while the other five had been taken to specialist and mainstream dental services. The parents of 13 children had faced no barriers in accessing dental services and six had. Twelve were said to have experienced difficulties related to their ASD when accessing dental services.

**Emerging themes** The authors generated themes and subthemes from their analysis of answers to the open questions and findings from the interviews.

The overarching theme concerns the approach and style of the dental practitioner, while subthemes relate to communication and environmental or sensory factors. In addition, the sub-theme of communication encompasses interactions between parents and dentists, children and dentists, and children and parents.

The subtheme of environmental or sensory factors encompasses the adaptations dental services should make for children with ASD, the explanations about what dental services involve that dentists
should give to such children, and the acceptance by
dentists that the needs of children with ASD differ
from those of other children (Figure 1).

Opinions
The data covered a wide range of opinions about,
and experiences of, how dentists interact with
children with ASD. Most parents said that their
dentists had not adapted their practices to the
children’s anxieties. There was a wide range
of views about how dentists interacted with children.
Most parents thought their dentists did not adapt
to their children’s anxieties.

‘The dentist that we saw, I didn’t find her
at all understanding of my child’s anxieties.
The dentist didn’t speak in any clear way’
(Questionnaire respondent 1).

‘Her demeanour and language and tone, were
far too hyped up, full of jargon and this made my
daughter terrified and uncooperative, even though
the dentist knew she was autistic’ (Interviewee 3).

‘Limited knowledge of how to settle a child
who has difficulties following instructions’
(Questionnaire respondent 5).

‘The dentist was not understanding. She did not
help a fearful child and my daughter would not
trust her as she said she had no confidence in her’
(Questionnaire respondent 3).

‘The dentist is quite brusque telling her she
is old enough not to be sitting on mum’s knee’
(Questionnaire respondent 13).

Excellent and helpful practice was also described,
however.

‘When the dentist used social stories it
was so much easier for the child to settle’
(Questionnaire respondent 5).

Parents reported on the good practice of special
needs dental practice staff even if the environment
was no different from mainstream dentistry.

‘I felt more relaxed at the special needs dentist,
although principally the set up is the same, waiting
rooms, weird lights, sounds and smells, the staff
were more clued up about my son’s behaviours
and more tolerant of his fabulous oddness’
(Questionnaire respondent 15).

One parent reported frustration that their
dentist, in trying to relax their teenage son, actually
exacerbated his anxieties by talking to him

‘The main problem is that the dentist tries to put
kids at ease by asking them ‘easy’ questions like
‘Have you had a good day?’ or ‘Do you like school?’
These are really hard questions for my son and make
him nervous. It would be better to just stick to the
facts. It always starts things off on the wrong foot’
(Interviewee 2).

Communication between parents and
dentists had a positive impact on how the dental
care proceeded.

‘I worked with the dentist and used her older
sister and myself as role models to aid her
understanding our dentist always listened to
suggestions and allowed this family consultation’
(Questionnaire respondent 2).

Parents welcomed the intervention of dentists
who listened and sought the advice of the
parents before proceeding with the consultation
and treatment.

‘I think one of the main things is that the dentist
listens to the parents, because the parents are dealing
with the child all the time’ (Interviewee 4).

Parents wanted to be able to articulate to the
dentist how best to deal with their child.

‘After moving dentist and writing a two-page
explanation of what works and what doesn’t, things
have been okay’ (Questionnaire respondent 12).

‘So gradually he [the dentist] was really good
and he listened to me. I said this is what we need
do. I said to him that all of her reactions are to
scream like that. Don’t worry it’s not the dentist
that’s bothering her’ (Interviewee 3).

‘Listen to the parents on how it would be the
best way for the child to be supported through the
experience because the parents are dealing with the
child all the time. I know by just giving him that little
bit more time and explanations, possibly some visual
aids prior to going in, that he would definitely be able
go through and sit on the chair and actually have
that dental check’ (Interviewee 4).

Frustration increased when parents thought that
their advice and concerns were not recognised.

‘I had explained to the dentist that he had a
diagnosis of Asperger syndrome on a previous visit
and would need things explaining, but I am not sure
this was written down anywhere or if the dentist had
remembered’ (Questionnaire respondent 4).

The interaction between parents and their
children in the dental room can be helpful to
the dentist.

‘Our daughter needs both parents in the room
to provide reassurance throughout the examination’
(Questionnaire respondent 11).

Even with parental intervention some children
cannot settle at all in the dental surgery.

‘She completely shut down and was absolutely
terrified of everything. We couldn’t get through
to her at all’ (Interviewee 3).

Intense sensory experiences in the dental surgery
can create extra challenges for many children with
ASD. Parents reported both excellent and poor
practice in their child’s treatment.
The best experiences that parents reported focused on dental staff accepting the child and the advice of parents and the child’s condition, and adapting their practice to accommodate the child’s needs.

‘They are knowledgeable about my son’s needs, and are able to make allowances for him’ (Questionnaire respondent 8).

‘Our dentist was really good by letting the whole family go in, model it for her and then I would hold her down on the couch, I held her mouth open, and luckily she screamed all the time which meant that the dentist was able to have a good look, but actually the dentist didn’t touch her at all, at first, until it was kind of okay to touch her over a period of time’ (Interviewee 3).

Parents also reported a lack of acceptance, understanding and recognition from the dentist.

‘My son has big issues with brushing and cleaning teeth. He won’t use paste at all in any flavour as doesn’t like taste or texture (huge food issues too). He hates the feel of toothbrush and won’t use either manual or battery brushes. He is nine years old and five foot four, and on last visit, the dentist suggested that I pin him to the floor and force the brush in his mouth! It has also been suggested that I neglect my son as he always has substantial plaque (for reasons noted above) and therefore I am neglecting him by not forcing him to brush’ (Questionnaire respondent 14).

Adapting facilities to soften the sensory overload experienced by some children with ASD could help with their oral care. One parent explained how the building did not settle her child’s anxieties.

‘As soon as we went it was really an imposing building to start with [sighs] … it just, she hated it, from the second we got there it was just horrendous, so she just wouldn’t even let anybody go anywhere near her’ (Questionnaire respondent 5).

‘The experience of having to travel so far and into a very busy city, which is terrifying for my daughter as it is, and then the hospital was huge and imposing, the fears were in place before we even got to see the consultant. Their approach was good and understanding but the environment was not’ (Questionnaire respondent 15).

When adaptation took place the benefits were demonstrable and recognised.

‘My son’s dentists are extremely patient with him and we appreciate this enormously. Although not experts in ASD they clearly make allowances. We found them to be quite brilliant. On reading in his notes that my son was autistic, a small private waiting room was immediately offered with a comfy bean bag and a TV. This allowed my son to be himself and relax’ (Questionnaire respondent 8).

Extra time to explain processes and procedures worked well.

‘Special sessions for the child to become familiar with equipment, smells, the room etc,’ (Questionnaire respondent 15).

‘She just had an appointment this morning, so she’s on her third appointment now and we, we’re doing that very regularly and they [special needs dental staff] have been absolutely fantastic’ (Interviewee 1).

‘The special needs dentist only asked my son to sit in the chair on the first visit. They took their time to explain the instruments and what they needed to do. They sent me a social story in a cartoon format which they made especially for us so that I could go through it with my son before the next visit. On the second visit my son took less time to settle and the dentist was able to treat him’ (Questionnaire respondent 5).

Discussion

This article reports on a pilot study so its findings must be interpreted in the context of the small sample who participated. Taking his limitation into consideration, the themes identified were evident in the data collected, which merits the expansion of the study to include a wider population.
Findings suggest that parents who reported positive experiences felt they were listened to by dental staff, and practice was altered to meet individual needs, while negative experiences were often caused by a breakdown of communication between the child, parent and dental staff, a lack of practitioner’s awareness of ASD or reluctance to adapt practice to cater for sensory difficulties.

Estrella (2013) emphasises that some parents may be reluctant to communicate their concerns in view of difficult experiences they have encountered accessing other services.

As Box 2 shows, strategies were suggested by parents to help other parents who are having difficulties with their children with ASD in accessing dental care. These strategies naturally mirror the themes generated from the data. Some strategies support communication, some support sensory issues and others support or address both.

Findings in this study demonstrate that there is excellent dental care being provided by mainstream as well as special needs dentists. However, there is also evidence to suggest that some dental practitioners are not approaching the care of children with ASD with sufficient understanding to communicate or adapt their practice to cater for individual needs. The adaptation of practice to support the needs of children with ASD was recommended in the Department of Health’s (2010) Fulfilling and Rewarding Lives: The Autism Strategy.

If staff do not know about autism and how it affects behaviour and responses, they can have no idea of how to adjust the way they deliver services. Recently published guidelines from the National Institute for Health and Care Excellence (2013) provide advice for healthcare professionals on how to manage and support children with autism, and communication is a central component of this: ‘Good communication between healthcare professionals and children and young people with autism and their families and carers is essential.’

Delli et al’s (2013) recent literature review of children with ASD receiving dental care recommends that dentists must have a deep understanding of autism and the flexibility to modify their approach to meet the needs of the child. The National Autistic Society (2013) already offers valuable advice to those with ASD and their parents, highlighting the best strategies and resources available to help with their dental care.

**Conclusion**

In light of the project findings discussed in this article, the authors intend to undertake two national studies of opinions about dental services for children with ASD, one involving parents and the other dental professionals. Their ultimate aim is to draw up further guidance about this area of practice.

**Implications for practice**

- Parents of children with autism spectrum disorder (ASD) should be encouraged to advise and help other parents who are having difficulties.
- Dentists should adapt their practices to meet the needs of children with ASD, explain what their services involve to such children, and accept that the needs of children with ASD differ from those of other children.
- If necessary, examination environments, communication techniques and pharmacological adjuncts should be prepared before children with ASD visit.
- Appropriate training of dentists and staff should be routine.

**References**


