ASD and paediatric dentistry

I am a paediatric dentist who has been working for over 20 years with the families of children who are on the autistic spectrum. The following article is based not only on my own experience but also the feedback from those families whose children I have seen grow up under my care.

Oral health and dental care for the autistic child

Let’s face it, going to see the dentist is not usually a great experience for anyone. Imagine what it must be like for the autistic child?

We are all familiar with the diagnostic criteria and problems concerning ASD. However, what many professionals (including dentists themselves) need to understand is the impact of these problems on the ability to maintain good oral health and delivery of dental care.

In this respect, I believe autism to be unique.

When discussing health related behaviour it is invariably good practice to focus on positive aspects. In the case of ASD it is probably more helpful to consider some of the barriers and problems and how they may be overcome.

Late diagnosis

The average age of diagnosis is relatively late compared with other more “obvious” conditions and in many areas there is an extensive waiting list for the definitive assessment. Consequently, late identification often results in delay in contact with dental services and therefore preventive and behavioural strategies don’t start early enough to be truly effective. This can be a problem because it is widely recognised that most behavioural interventions work at their best when started early in the child’s life. It is also important to recognise and address unwanted behaviours before they become entrenched in the child’s repertoire.

Early contact with dental services is absolutely essential for children with ASD and a paediatric dentist should be part of every Multi/Interdisciplinary Child Development Team. The individual
team members should be routinely and actively signposting any child who is referred to them with possible “social and communication problems” (so often a pre-diagnosis of ASD).

It is also important for dentists themselves to be aware of being in contact with support groups and networking. The power of “word of mouth” shouldn’t be underestimated either. In my surgery, we are used to parents telephoning us and asking for an appointment for the “autistic dentist”!

As the diagnosis of ASD is one which affects the whole family it is also important to identify other siblings. Not only might they also be on the spectrum and perhaps undiagnosed, but also, their dental needs are sometimes eclipsed by those of their sibling.

**Sensory issues**

Children with autism often process sensory information differently and sensory issues can be a main anxiety trigger for the autistic child at the dentist. A child may be hypo or hyper sensitive to sights, sounds, smell, taste and touch all of which are challenged in a dental surgery.

In addition there may be difficulty in expressing pain and the response to pain may be different and so dentists need to look out for other indicators of pain – sleep disruptions, random emotional outbursts unusual for the child, or problems eating.

Many children have sensory seeking behaviours and may put various objects in their mouth including, but not exclusively, fingers. Parents are often worried that such activity is a sign of pain in the mouth. This needs to be excluded of course.

The dentist should be asking specific questions relating to any possible sensory issues to help identify behavioural triggers both positive and negative. This should include questions relating to feeding and eating. A pre-appointment questionnaire can help with this, in addition to a verbal interview. Only by asking detailed questions can the dentist begin to understand the child’s requirements and begin to address them.

Too much sensory information can cause “meltdown” and the dental surgery is the perfect place for this!

**Co-morbidities**

NICE states that 70% of children have co-morbid mental and behavioural disorders and 41% had two or more. ADHD, anxiety, OCD and depression can all affect the oral health and health care delivery.

Epilepsy, both its treatment and monitoring, can be a problem for dentists. Not only does epilepsy sometimes lead to damage of the front teeth during a fall, but also the child may be upset and confuse the dental surgery with the clinical environment where blood tests are undertaken. Other co-morbidities may have more specific impact on oral health e.g. Down syndrome.
Behaviour

A dental surgery can present a huge challenge as a new experience for an autistic child. The child’s behaviour may be unusual, disruptive and worrying (e.g. self-harm) for everyone concerned with the child’s care.

The effect of sleep disruption in families shouldn’t be underestimated and interaction with the tired child and parent needs to be both sympathetic and measured.

The parent may feel the need to resort to anything to help influence the child’s behaviour and avoid conflict. This may include use of sweets or biscuits. It is widely acknowledge how powerful these can be even amongst dentists’ children!

Therapies

There are many therapies reported to be of value in the management of ASD. I will briefly consider three of the most common therapies as examples of how these can impact directly on oral health and care delivery.

Medical

There are great differences in prescribing practices in different countries. Many of the drugs can have an effect on oral health e.g. not all are sugar-free, some can cause dry mouth and others can result in an increase in appetite.

All medication should be sugar free or in tablet form wherever possible and appropriate advice/supplements given if the mouth becomes dry. Low sugar snacks should be encouraged wherever possible if appetite increases.

Timing of appointments is also important to ensure that the medication is still fully active when the child attends, especially if there is ADHD as a co-morbidity.

Diet

Most common is the gluten and casein free diet. The usual safe snacks recommended for teeth are bread and milk products. Dentists therefore have problems giving advice as alternatives are sometimes difficult to access and expensive.

The dentist must think imaginatively about dietary advice and fully consider each child’s personal preferences and requirements in addition to the parent’s choice of dietary regime.

Behavioural

Some approaches (Applied Behaviour Analysis – ABA) involve using reinforcers which, if they are sugar based, can cause dental decay.

Other therapies may have implications for oral health and treatment. Examples include the avoidance of fluoride, plastic and metal dental restorations and in the prescription of tetracycline to a toddler!
Some behavioural approaches can be utilised to encourage oral hygiene and compliance in the dental surgery. There has been increasing recognition of this recently with two important papers having been published.


This states that basic behaviour management techniques currently used in dentistry are not consistently effective for patients with ASD and it is important to know about each patient's behavioural characteristics and parents’ level of involvement.


This paper stresses that dental management of an autistic child requires in-depth understanding of the background of the autism and available behavioural guidance theories. The dental professional should show flexibility in their approach and modify this to the individual patient needs.

I welcomed these publications as they echoed not only my experience, but also the feedback I was receiving from paediatric dentists all over the world.

It has been stated that the internet is the second most popular source of health care guidance after the physician, see *Treatments for Neurodevelopmental Disorders: Evidence, Advocacy, and the Internet* (*Di Pietro et al 2013*). I believe that the dentist has an important role to signpost parents to evidence based resources and accredited professionals in this field.

**Learning difficulty**

The dental management of children who are learning disabled can be a great challenge. Communication with children on the autistic spectrum who are also learning disabled requires experience, appropriate training, patience and time!

**Anxiety**

There is a great deal of anxiety associated with a dental visit and much of this can be managed through good communication. In my experience much of the negative and challenging behaviour seen at the initial appointments with an autistic child is because of anxiety.

Parental anxiety can be due to their own personal experiences, and sometimes unrealistic expectations. There is evidence that some parents are reluctant to take their child with ASD to the dentist because of concern about how everyone will react in this new situation.

An ability to find a dentist with the skills or willingness to work with people with disabilities was the most frequent reason cited by caregivers of children with ASD for not having a regular dental provider (*Brickhouse et al 2008*).
The dentist too can be anxious. They may witness disruptive or challenging behaviour in the waiting room and feel concerned, scared even! Much of the anxiety of the child, parent and the dental staff can be managed with the appropriate communication and planning.

A pre-appointment letter/questionnaire has many functions. Not only does it give the dentist valuable information but also it sets the scene for the parent and can address unrealistic expectations. Questions asked should include ones on communication aids, dietary issues, therapies, likes and dislikes.

It is an opportunity also to explain that the approach to the dental management of the child will be measured and that the dentist will firstly need to learn about the child. Parents find this helpful as “patience” and “having enough time for their child” are often quoted as being important qualities shown by the dentist.

A leaflet or printed information may be also sent or given which include FAQs on ASD and dentistry/oral health. A brief “hello” visit to the surgery might be suggested and encouraged beforehand either with or without the child so that everyone feels prepared.

Communication

Communication is again problematic due to the child’s limited speech and language and some children are non-verbal. The dentist can find it difficult, as the language and approaches that they have been taught to use with children often doesn’t seem to have the desired effect.

Also the child and parent may be using communication aids that the dentist is not familiar with:

- Makaton
- Picture Exchange Communication System
- communication boards
- voice output aids etc.

The child doesn’t understand the common words, phrases and perhaps humour, that dentists usually use when treating children in the dental surgery. Asking them to jump on the chair can have disastrous results as can be imagined!

Impaired communication has an impact on all aspects of dental management and there is a well-researched link between communication and behaviour.

Communication is essential in building up good relationships and reducing anxiety. The pre-appointment questionnaire can elicit information about routines and rituals and preferences which dental staff need to consider in their approach to the child.

The dentist and other staff need to familiarise themselves with alternative forms of communication e.g. Makaton, PECS, social stories, widget symbols and apps. The NAS provides useful guidance on how health professionals should adapt their verbal communication when managing a person on the autistic spectrum.
Examples include:

- speaking slowly
- leaving time for processing
- omitting unnecessary words
- sticking to facts
- being realistic and accurate about time frames.

**So what are the dental treatment options for children with ASD?**

**Behaviour management**

This would be the ideal approach, however, as previously stated this can be challenging. Many of the usual child management techniques simply don't work for children on the spectrum (Hernandez and Ikkanda JADA March 2011). The child’s behaviour needs to be managed so that preventive practices can be put into place and also so that some dental treatment can be carried out if required.

Integrating elements of ABA can be useful to help a child become familiar with the dental visit. Linking the desired behaviour to some sort of reinforcer or motivator can be useful using the “First and Then” approach.

It is also important to remember that touch can be an important motivator for some children. Squeezing limbs or massage can be a powerful reinforcer.

The success of non-pharmacological management of the autistic child depends on a number of factors which include level of learning disability, ability to communicate, experience of the dentist and time pressures (for both dentist and family).

**Inhalation sedation**

Magic wind or “happy gas” can be used successfully with high functioning children where communication throughout the procedure is possible.

**Intravenous sedation**

This is not used widely in the UK for autistic children.

**General anaesthesia**

This is used when a child requires actual dental treatment and is the most commonly used approach in the UK if a child needs extensive treatment or is quite young. As might be imagined, this is a highly stressful procedure for all concerned for many reasons including unfamiliar environment, and the need to starve the child or for the child to take premedication. If treatment is carried out under general anaesthesia, it needs to include preventive as well as curative elements in order to “future-proof” the child’s oral health. It should be followed up with rigorous customised preventive regimes and support.
It is obvious from the preceding paragraphs that the dental management of the autistic child presents a number of challenges for the dental profession and the family. Remember that dental disease is completely preventable. It is for this reason that I believe that the best treatment for the autistic child should actually be no treatment.

Of course, it would be naïve to think that dentists simply telling the parents to limit sugar in the diet and brush teeth twice a day with fluoride toothpaste is enough. This approach doesn’t work very well with the neurotypical population, so why should it with children on the spectrum?

The autistic child requires preventive advice relating to diet and tooth brushing which is “bespoke” and highly customised. It needs to fully consider and address the individual child’s requirements and idiosyncrasies as well as the family’s wishes and ability to comply.

Brushing teeth needs to start as early as possible but difficulties relating to understanding, behaviour and sensory issues need to be explored and addressed imaginatively. Behavioural approaches such as ABA can be used and adapted to help with tooth brushing. Accurate and evidence based information should be given to the parent regarding the correct use of fluoride toothpastes.

Children with ASD often have feeding/eating problems and may also eat a significantly narrower range of foods. Advice relating to safe for teeth foods/drinks and snacks need to acknowledge this in addition to the parental wish to try therapeutic diets/supplements. Confectionary is often used to reward “good behaviour” and to avoid conflict with the child in social situations.

Dentists need to be sympathetic with the parents whilst exploring safer alternatives for the teeth. It is also important to acknowledge the great variation in parenting practices which we witness in a multicultural society.

In conclusion

It is obvious that early referral and oral health support is imperative for families of autistic children.

Although the autistic child should ideally be seen with the rest of the family in a high street dentist setting, the reality is that this is usually not the appropriate environment for the majority of autistic children. It is therefore important that children are referred to the appropriate dental service as soon as they are identified by other professionals; ideally whilst they are awaiting a formal diagnosis. In most areas, this means referral to the local Community Dental Services. The staff working in this sector of the NHS should have not only the expertise and training, but also the flexibility to support those crucial early preventive steps with the child and family.

Further information

Dr Bellis will be discussing more on these topics at the National Autistic Society’s Professional Conference in March next year, further information can be found here.