



The challenges of treating autistic patients

Autism UK states that over 700,000 people in UK are autistic, which means that 2.8m people have a relative on the autism spectrum. Those living with autism face some specific yet complex challenges, for patient, parents and family alike.

One of these challenges is undoubtedly a visit to the dental practice. After all, poking around in someone's mouth puts those without autism off – see the one in four who cite dental phobia. David Westgarth spoke to Dr Jacqui Shepherd, a Lecturer in Education at the University of Sussex, and Dr Jennifer Parry, a Paediatric Dentist Consultant for the Sussex Community NHS Foundation Trust Special Care Dental Service, about a small scale scoping study (funded by the University of Sussex) which they carried out with parents, dentists and some autistic children. They talked about some of the challenges faced for families and dentists – and the implications for every day practice.

‘The underlying problem lies away from the dental practice’, Dr Parry said. ‘A report earlier in the year identified that just £4m is allocated for autism research, which is equivalent to roughly £6 per person in the UK. That is not acceptable. The annual cost of failing to support autistic people adequately in the UK is estimated to be £32 billion.

‘Much of the funding is allocated to identifying a cause. More needs to be allocated to social care and supporting the growing number living with autism. There are pockets of research out there that offers information on what families should do when it comes to a visit to the dentist, but there's not a lot out there for practitioners. An autistic patient can be a real challenge,

Dr Jacqui Shepherd

Jacqui is a Lecturer in Education and is Course Leader for the BA in Childhood and Youth: Theory and Practice. She also co-ordinates the special needs training provision for trainee teachers within the department and supervises MA and doctoral research students with interests in special educational needs, autism, disability and inclusion.



Dr Jennifer Parry

Jennifer is a Paediatric Dentistry Consultant at the Royal Alexandra Children's Hospital, Brighton and within the Special Care Dental Service, Sussex Community Foundation Trust. She is also Oral and Dental Specialty Lead within the NIHR Clinical Research Network Kent Surrey and Sussex. Jennifer is collaborating with the University of Sussex and University of Cambridge on projects to improve dental experience for children and young people with autistic spectrum conditions.



particularly in general dental practice.'

'If you take an autistic child that has a cavity, a large part of the treatment process will surround their behaviour', Dr Shepherd said. 'Quite often you find general dental practitioners referring to community dental services or straight to general anaesthetic, simply because it would be easier than managing atypical behaviour. That convenience comes at a price – travel, inconvenience, secondary care costs. With better education, knowledge and awareness – particularly for those in the general dental setting – there could conceivably be fewer referrals out of general practice.'

Sensory challenges, unpredictability and anxiety caused by the nature of a dental examination and environment can contribute to a 'perfect storm' for autistic children. Research has identified that they process sensory information in a different way, and sensory overload can be the main trigger for their anxiety. Their ability to express pain and response to it may be also different, which is a worry for parents and dentists alike. So who needs the higher level of support – parent, practitioner or patient?

'All of the above need help in certain areas of encouraging the child to visit the dentist. Better parent-practitioner communication before, during and after the visit would make a huge difference. The practitioner knowing how to set the right environment would be great on the back of that. If the parent remains calm and doesn't unnecessarily change routine, that would help keep the patient calm.'

'A patient's behaviour will vary hugely according to where they are on the

spectrum. One size does not fit all, so this collaborative approach is absolutely necessary. We know that autistic children may have impaired communication and additional co-morbidities, and it is a challenge for practitioners.'

So how treating autistic patients in the dental setting be improved?

'Hospitals and community dental services have a very detailed medical history form that often gives the option to list autism', Dr Parry added. 'While it is worth noting that community dental services have significantly more flexibility in the way they can treat

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patients compared to general dental setting, much of that flexibility comes from the work they do in the lead-up to an appointment. Systems of disclosure of autism should be made more transparent on medical history forms so that parents are clear where and when to disclose and so that dentists have a full understanding of the child's developmental condition and proclivities.'

Dr Shepherd added: 'Quite often practitioners in general practice need to rein in their expectations of what can be achieved during a dental visit. As part of their inherent professionalism, it is not surprising that dentists want to do a good job and fulfil their professional role to the highest standards but this does not always mean that every dental visit can be as successful as the last and particularly where autistic children are concerned. Of paramount importance is the success of the visit so that children are not scared to return and do not have negative associations with the dental practice. A pre-visit where no treatment takes place but introduces the patient to what a dental practice is like can have significant benefits in the long run.'

Building in successful strategies to dental visits is a theme both Dr Parry and Dr Shepherd were keen to stress would ultimately be a positive way to ensure that parents, children and dentists were able to feel that they had achieved something during the experience. However, both were also aware of the potential pitfalls for those working in general dental services.

'One of the barriers we have discovered is the UDA system', Dr Parry said. 'The

pressure to meet targets, pressure to see as many patients as possible and therefore the pressure to use time wisely may see the need for a pre-visit fall by the wayside. Would a practitioner claim for a UDA if an oral examination is not possible? Would it be appropriate to do so? These are grey areas that need to be cleared up, and they're areas that community dental services don't have to consider.'

Perhaps the biggest advantage community dentals services has over general dental services is the ability to adapt. Children with autism are highly likely to have sensory processing difficulties in some or all areas including hyper-sensitivity to sounds, smells, touch, taste and light and this adds to the challenge for parents trying to support their children through dental visits. That is why Dr Parry would recommend adaptations to dental environments – where possible.

'We're not talking about huge changes that will involve investment. Adaptations to your current environment can be quite simple. This could include re-thinking the necessity of strong overhead lighting, whether operation equipment needs to be ever-present and whether for initial routine visits or check-ups, autistic children could be seen in a more relaxed setting and using more portable and more directed lighting. Waiting rooms could also be more inclusive spaces. A walk-through of your practice from entrance to chair, for example, would help you to gain a better understanding of these considerations. There's a pre-visit information-gathering resource available on the BSPD website for parents to provide information about likes and dislikes of their child that's really helpful too.'

'Ultimately the bottom line remains that the profession needs more education on autism', Dr Shepherd added. 'Whether through formal Continuing Professional Development mechanisms or by more informal local arrangements where there are chances to observe community specialist or consultant dentists at work, the knowledge gap needs to be plugged. We already know parents are very well informed. If practitioners reach anywhere near the level parents are at, it would make for a smoother experience for everyone.'

'That's not to say there aren't pockets of excellence. There are many examples of good practice, both in the community and general dental setting. More research is needed, and above all else more funding to power the research and education.' ♦



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