



Parent Experiences of Taking a Child with Autism for a Dental Check up

This research summary was written by PenCRU and members of the study advisory group

Key Findings

- We asked 17 parents of children with autism aged between 4 to 13 years old, living in Somerset or Devon, what it has been like taking their children for high street dental check-ups.
- Dental visits were more successful when parents felt confident to advocate for specific needs of their children, the dental team were flexible in responding to parent's requests and the whole dental team were involved in providing a positive experience.
- The study highlighted the value of clear communication and the need for a better understanding of when and where to refer a child to specialist dental services should it be needed.

Who carried out this research and why?

Nicole Thomas is a dental hygienist and a mum to a child with autism. Nicole wanted to find out how access to high street dental services could be improved for autism families.

Nicole was supported by the team at Peninsula Cerebra Research Unit (PenCRU) a childhood disability research unit at the University of Exeter Medical School and Professor David Moles at Plymouth University Schools of Medicine and Dentistry.

Background

Children with autism are at high risk of developing tooth decay because of the difficulties they have in carrying out self-care such as tooth-brushing.

Previous research looking at ways to help children with autism visit a dentist was limited to the dentist's perspective or only looked at individual children's experiences, and was not carried out in the UK.

We wanted to gather parents' experiences of taking a child with autism for check-ups with high street dentists to better understand how we can help these families have access to a local dentist, and their experience of care.

What did we do?

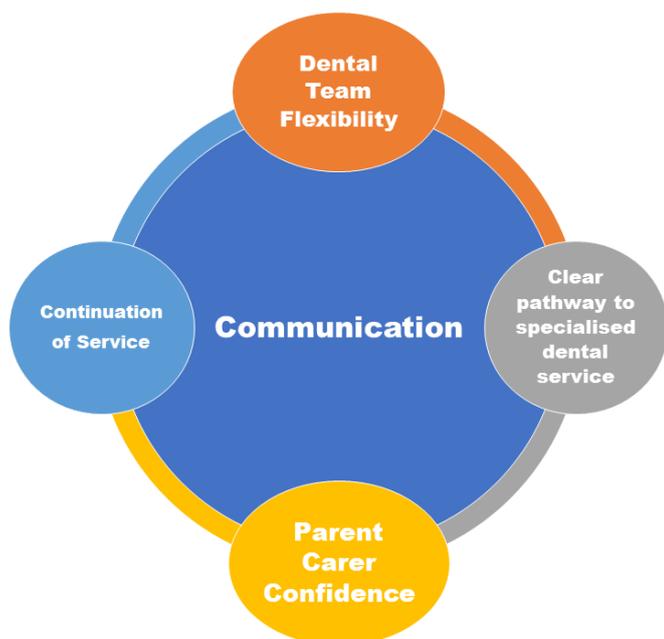
We set up a Parent Advisory Group with parents of children with autism to advise us with every stage of the research. Some of the group helped us to design the study and analyse and interpret our findings, and helped to write this summary.

We interviewed another 17 parents, with a total of 20 children with autism, on their experiences of taking their children to the dentist and ways they wanted dental services to be improved.

Three of the children had a presumed diagnosis of autism and seventeen had a formal diagnosis. Sixteen were boys and four were girls and all ranged in age from 4 to 13 years old.

What did we find?

We found that five factors needed to be present to increase the chance of dental check-up success. The diagram below shows how these factors are linked together with communication being placed in the middle.



Parent confidence was undermined when parents assumed the dentist's education had provided enough training to deal with children with additional needs. Parents consequently didn't feel they could question the dentist when issues arose.

Some parents, despite confidently advocating for their children, experienced reluctance from the dental team to make minor changes. Therefore, despite their best efforts, dental visits were largely unsuccessful. Dental teams that took time to respond to the needs of the children that were expressed by parents had more positive experiences. This highlights the need for flexibility of the dental team.

Check-ups were also good when the whole dental team became involved in the care of the child. Helpful strategies included providing information on what to expect before a check-up and making thorough notes so parents did not have to repeat themselves at every appointment. This continuity

before and after a check-up was valued by participating families.

In addition to the above factors, dentists knowing when and where to refer a child to specialist dental services avoided delays to children getting the dental care that was appropriate for them outside of the high street dental setting.

Although it wasn't seen as of paramount importance, parents did want the dental team to have a better understanding of autism especially the impact a dental visit can have on them as a family, from the amount of preparation it takes to the fallout should a dental visit result in a meltdown or similar.

What are the strengths and limitations of the study?

- We worked closely with our Parent Advisory Group throughout the project. This helped us design research that is relevant and useful to families and people that work with them.
- We have been able to talk to parents who are experts on their children with autism and therefore now have a better insight into how the dental profession can improve their services for these children.
- A limitation of the study is the small sample, lack of cultural diversity in South West and all respondents were mothers which may limit the applicability of these findings.

What next?

This study has been accepted for publication in an international dental journal. We will make the findings of the study available to a broad range of people. Nicole will be working with Plymouth Dental School to provide training to dental students based upon the findings from this study.

Where can I read more?

This is a very brief summary of the research. **If you would like a copy of the full report, please contact: pencru@exeter.ac.uk**

The team that carried out the research are: Nicole Thomas, Sharon Blake, Chris Morris and David Moles with support from the PenCRU Family Faculty Parent Advisory Group.

The research team are all part of the Peninsula Cerebra Research Unit at the University of Exeter Medical School or Plymouth University Schools of Medicine and Dentistry.

This research was funded by the Oral & Dental Research Trust; PenCRU receives funding from Cerebra and the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care South West Peninsula (PenCLAHRC). The views and opinions expressed are those of the authors and not necessarily those of the Oral & Dental Research Trust, Cerebra, the NHS, the NIHR or the Department of Health.