



Dentistry for Children with Autism Project - Meeting 1

01/06/2015 St Lukes

Family Faculty: Annette, John, Maureen, Maria, Karen, Josie **PenCRU:** Nicole, Chris, Kath, Sharon;

Apologies: Lisa, Carly, Ursula (Family Faculty) and David (Plymouth University)

Overview

- Nicole introduced and described the background to the research.
- We discussed what can impact access to the dentist and how to recruit participants for the study.

What next?

- A next meeting will be held in July to look at draft participant information sheets and interview questions to gather feedback before applying for ethics approval.
- If you have any comments or come across any information or resources relevant to the programme, please contact us pencru@exeter.ac.uk or phone (01392 722968).

Introduction and Background to the Research

Nicole has been working as a dental hygienist for eleven years and also has a three year old son with autism. He was diagnosed early, due to Nicole having autism in the family and recognising (and pushing for authorities to check) the symptoms.

Nicole now mixes with a large number of families with children with autism and when they find out what she does for a living, they tend to share their dentistry experiences and challenges with her; most of which aren't positive and do not reflect well on the dental professions!

Nicole has found studies which have looked at the barriers to dental care for children with autism; and reading as a dental professional, they make very interesting and valuable points. However, as a parent of a child with autism, she recognises that the dental professional perspective isn't always conducive to helping families as much as it is intended to.

The participant numbers in these studies also tend to be low because co-operation for a child with autism is very challenging for a number of reasons! So, the research project Nicole is conducting, with the wonderful (Nicole's words!) help and guidance of the PenCRU team, will hopefully turn things on its head and look primarily from the parents'/families perspective in helping their children access primary dental care (local family dentist). As both a parent of a child with autism and a dental professional, the research will hopefully result in an outcome that will benefit both worlds.

In response to Nicole's introduction to the research, the group shared both positive experiences (parent working with dentist to prepare for visits/putting strategies in place before hand, dentists with 'kids clubs' and 'dental games' children can play at the dentist) and negative experiences (children refusing to go to the dentist and battles to clean teeth at home).

Nicole asked the group if they felt that sensory processing may be a key difficulty accessing dentists and the group felt that a key concern is to reduce anxiety.

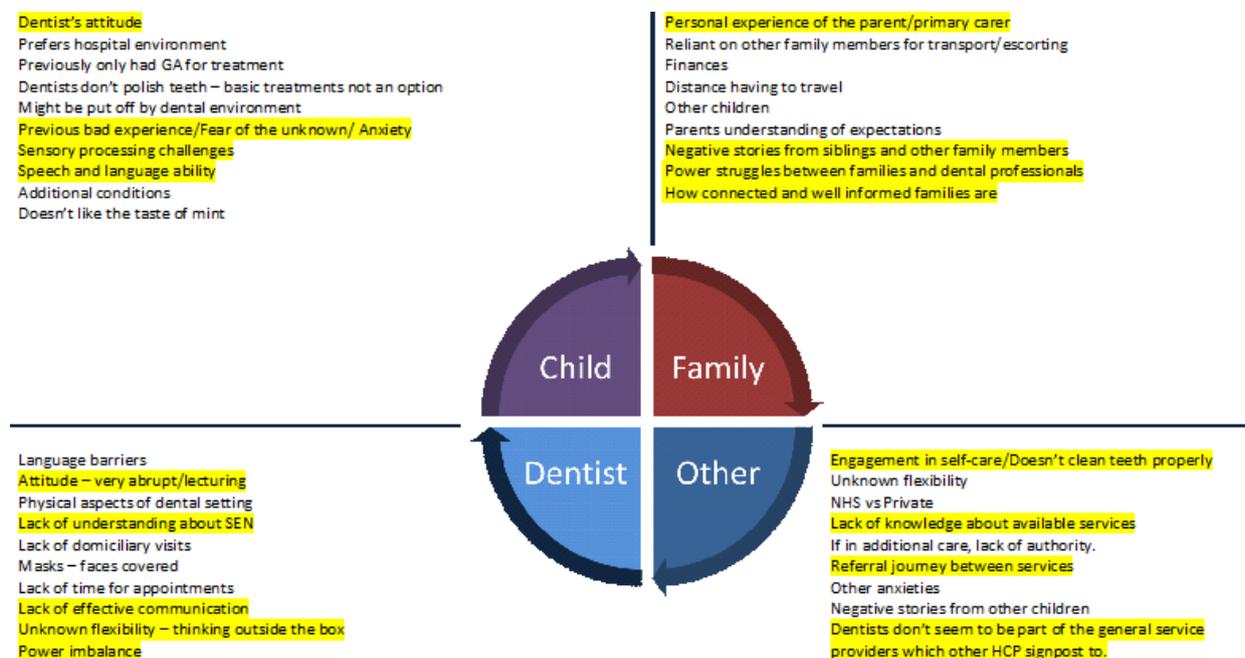
The group discussed the importance of dental professionals having an understanding of special needs throughout the practice; from receptionist, nurse, as well as the dentist. The group also discussed having a lack of information about what support and choices were available. For example, Nicole explained that a check-up could take place standing-up rather than sitting in the chair and the group agreed that not knowing that these options or that more flexibility was available affected access to dentists.

Discussion 1: What are the important factors that impact access to the dentist?

In small groups we each discussed what particular issues for the child; for the family; about the dentist and any other factors could impact access to the dentist.

Key factors included:

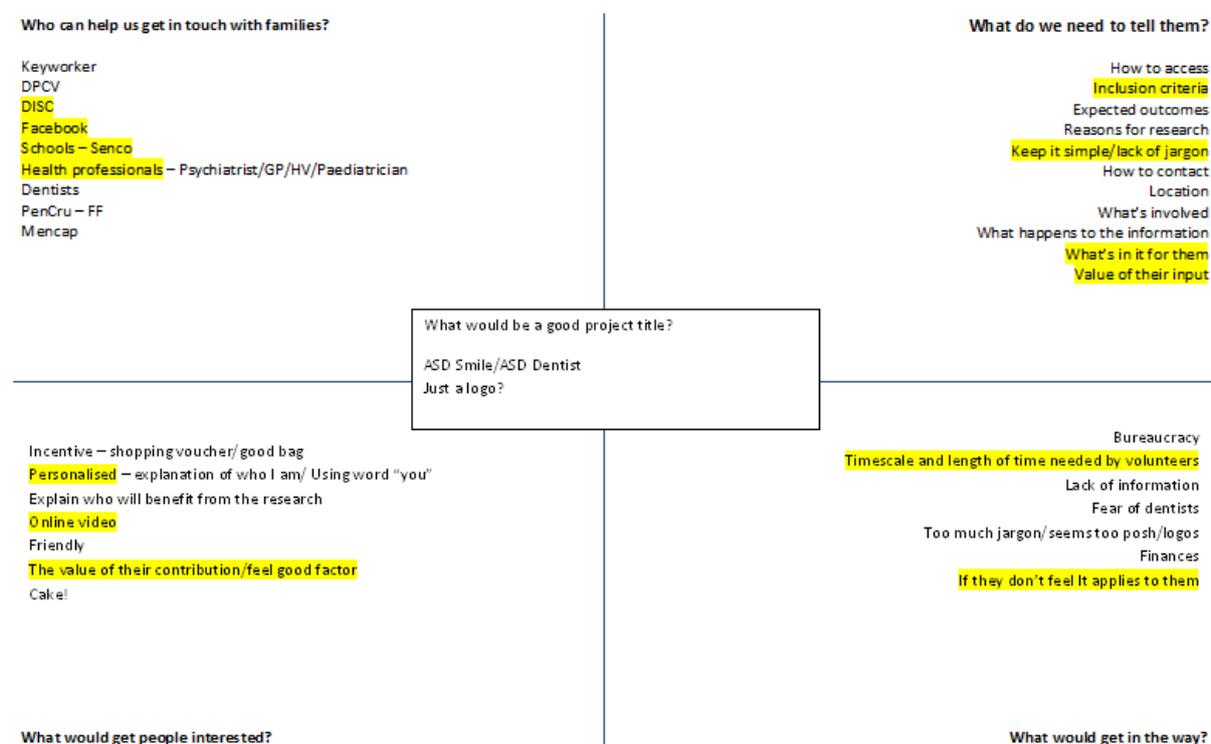
- Attitude and communication skills of the dentist
- Dentist understanding of special needs and their flexibility in practice
- Prior experiences of dentists both for the family and the child
- Power imbalance – families uncertain of asking the dentist as expert to modify their practice
- How connected and well-informed families are about dentistry options/available services
- Child’s speech and language ability, sensory processing challenges and anxiety
- Child’s engagement in self-care and parent’s embarrassment/fear of judgement about state of child’s teeth and behaviour.
- Referral journal between services/dentists not being seen as part of ‘standard’ health services



This information will help to decide on what questions to ask and what information we need to collect from participants.

Discussion 2: Recruiting Participants

In the second part of the meeting, we discussed who we could contact about the study, what we would need to tell them, what would get people interested and what could stop participation.



- The group agreed that it would be better to contact specific groups rather than advertise with posters in dentists or schools. Although it was recognised that this then might miss some families, the group felt that participants would volunteer from hearing about it from others (word-of-mouth).
- The group discussed sending an invitation email to Sencos, Special Schools and key workers/social workers to let them know about the research/passing the information on to interested families. Autistica UK may also advertise the opportunity.
- The group emphasised the importance of using simple words and avoiding words like ‘strategies’, as well as being clear what is required by participating and what the benefits of participating are.
- It was suggested that Nicole creates a short film of her describing the research which could be posted on the PenCRU website and families who prefer visual information could access it.
- Nicole was keen to include families whose children do not have a diagnosis but have sensory processing needs but the group felt that enough participants would come forward if she limited inclusion to those with a diagnosis. It was agreed that this initial project would be specifically about children with a diagnosis of autism but later projects could have different inclusion criteria.
- The majority thought that families would want to contact the research team by email, but also provide an office tel number and provide the option to send hard copies of information. No-one felt it was necessary to provide a mobile tel number.

Our thanks go to everyone who contributed to this meeting. If you have any comments you would like to add, please contact us, details at the top.

Next Meeting: Monday 13th July 10am to 130pm Room G27, Exeter Medical School Building, St Lukes