

Shaping Our Lives on behalf of the Win-Win Alliance 16th April 2019

# Special Care Dentistry Focus Group Report

# Hearing from Disabled People

## Attendees

The focus group was facilitated by Becki Meakin, General Manager of Shaping Our Lives on behalf of the Win-Win Alliance. The Win-Win Alliance is a member of the VCSE Health and Wellbeing Alliance and is a consortium of user-led organisations including Disability Rights UK, NSUN, CHANGE and Shaping Our Lives. The Win-Win Alliance provide expertise on the involvement of disabled people in shaping health and social care services.

There were seven disabled people in attendance with a range of impairments including visual and hearing impairments, chronic illness, mobility impairment, cognitive impairment, people experiencing distress and people with learning disabilities. There were three support workers present and one transcriber. Three people did not attend on the day.

Prior to the focus group Becki had explained to the NHS team the barriers to getting people with multiple impairments and health conditions to attend the focus group. Becki has spoken to several people including someone experiencing severe fatigue, someone of restricted height and a representative of people with challenging behaviour. Some of their comments have been added and Becki has connected the team to the Challenging Behaviours Foundation.

## Introduction

The project is an NHS England project which is about how special care dental services could be redesigned to work better for patients.

## Summary

* There is very low awareness of special care dentists and the services they offer.
* Many disabled people are able to get their care from a local NHS dentist.
* Disabled people who have multiple impairments and/or health conditions may not be able to overcome the barriers to visit a local dentist and would be prepared to travel further if their access needs would be met.
* Disabled people have better dentistry experiences when they have developed a longer term relationship with a dentist, they trust that dentist and the dentist practice is making some access adjustments for them.
* Not all people can advocate for their own access needs and there needs to be a process of collecting information about what reasonable adjustments are needed and ensuring that these are referred to when there is contact with the patient.
* It is important that all staff in a dental practice have had Disability Equality Training. A poor experience with a receptionist in a practice can stop someone from attending again.
* Cost can be a barrier to regular dentistry treatment. There is little awareness of help with dental costs for people on a low income.
* Practice recommendations need to be developed that include flexibility about the time of appointments for people who need a supporter to take them to the dentist and longer appointment times for people who need things explaining in a different way.

Is there a way that special care dentistry could be accessed by more people, perhaps through special care dentists seeing patients in a high street dental practice one day a week, as a form of mobile service

## Q1: How do you feel about the dentist?

- I get worried about going to the dentist.

- I find it confusing.

**"I have to ask them 2 or 3 times to explain it to me properly. I don’t understand it the first time. It takes a couple of times to go into my brain."**

- I do not know how to fill in the forms.

- It is a daunting and stressful experience.

- You have to self-advocate about your access needs (please note, many disabled people are not skilled in self-advocating and/or do not have the confidence to show others how to be inclusive).

**"As soon as you enter the room both the dental assistant and the dentist get stressed up, knowing how to guide someone with no sight. Even to guide me to the chair becomes a drama! How do we tackle this guy, he might fall down."**

- The dentist does not know how to explain things in an accessible way.

**"The critical part for me when an x-ray is taken, the dentist will talk me through it but then they say things like ‘see this one, see this colour’ which doesn’t help" (visually impaired participant)**

- I do not get information and appointments in an accessible format.

**"They have a system where they send reminders to my phone, but that is inconvenient for me because I don’t read."**

**"They should send me a dentist card through my letter box so that I know when my appointment is, or to phone me."**

- Reception staff are not always trained in how to work with disabled people.

**"we have two receptionists; one is well trained and can guide me and the other isn’t. I don’t know who I am going to get."**

- I need more flexibility about appointment frequency and the time of my appointment.

"time of day is important because if I need a supporter with me and they are working at that time on the day of my appointment, then I have to go on my own."

- I would like to see the same dentist each time so I do not have to explain my impairments and health conditions each time.

**"Once I got to know my dentist I am happy to go."**

## Q2: What type of dentist have you been to?

- Nobody in the room had been referred to a special care dentist.

- People had chosen a local/nearby dentist.

- Some people had been to hospital and/or children's specialist dentist at some time in their life.

- There was confusion about what a salaried dentist is.

**"At the moment I am with a salaried dentist if that means a private dentist?"**

* does everyone think a salaried dentist is a private dentist?

- All agreed [in fact salaried dentists are employed by Community Dental Services also known as Salaried Services or Special Care Services and provide NHS care].

* Has anyone been referred to a special care dentist, someone who could meet their access needs better?

- Nobody in the room had been referred to a special care dentist.

Their purpose is to provide dental treatment for people with additional needs. You can be referred by a high street dentist, or a doctor or via a carer. Sometimes called a community dentist. They are not a specialist like an orthodontist, but they are specialist in supporting people who need extra support to access care.

**"wouldn’t it better to call them additional care dentists? Not special. Too much like special needs education. Special needs is different and very alienating."**

There was then a general discussion to clarify the role of a special care dentist, how you can be referred, how much they cost and how to find one.

* Should dentists be collecting customer experience feedback?

- There was poor awareness about the Friends and Family Test among the participants.

**"I went to the same dentist for 10 years but I was never asked what the experience was like for me. It was difficult for me for access reasons."**

There was then a discussion about the communication training a dentist receives and the PHE representatives explained how this would differ between a high street dentist and a special care dentist.

- Some participants stated that dentists had been abrupt and did not appear to have an understanding of the communication needs of disabled people. One participant referred to providing training at their local dentist in how to communicate with people with learning disabilities.

## Q3: Why do you go to your particular dentist?

Most popular answers in order were:

- Near my home (reduces cost of travel and may mean people can attend without a helper).

- Easy to get to/I know the way (particularly relevant to people who need to learn routes such as visually impaired people, people with cognitive impairments and people with learning disabilities).

- They are nice, helpful and I trust them.

- Some people reported difficulty in finding an NHS Dentist that would take new patients. One person had joined a private practice near to home as the NHS provider could not take them.

- Chose a particular dentist because of cost (NHS rather than a private provider).

- Must be a dentist with accessible facilities (level access, lift etc).

**"I like my dentist because I know where to go on foot. Its near where I live. They make sure my teeth are nice and clean."**

**"where I go with my dentist they are very helpful at the desk. When I arrive they explain things. When I finish they print out my next appointment for me. The dentist himself is very nice, I’ve been with him a little while now, the assistant is nice, I feel relaxed in the room."**

## Q4: What would make it easier to go to the dentist?

Responses given:

- Accessible facilities including parking.

**"I need a downstairs surgery. It should be on the dentist’s website, what their access is like."**

- Accessible information in formats that are appropriate to each person.

**"I don’t get electronic information from my dentist, so that is difficult. The door is difficult to find. It is a busy street so I can ask people but I could not go to a dentist on a quiet street."**

- Knowledge leading to an inclusive attitude by all staff and a willingness to meet access needs.

**"I had to ask the dentist to help me in and out of the chair. I had to give them very specific instructions to help me sit up and get out of the chair, but they seemed too frightened to touch me. I got the impression they didn’t want to take a risk when I said I needed help. However it was basically a bad attitude issue which has meant I had to change dentists."**

- Flexible appointment times so people can arrange a carer or supporter to attend.

* has anyone ever been asked what their access and communication needs are?

- No one had been asked.

- Some people had asked for specific accessible communication such as email reminders and reported that the dentist was happy to provide this.

**"they keep our records so they should be able to record that information."**

Case study from a support worker (provided after the focus group):

"It is a real struggle for someone with profound mental health needs in a busy dental practice. Busy waiting room so noisy and stressful. Unfriendly receptionist always asking him for proof of benefits (for free treatment) which he would forget to take or lose the letter if he took the original with him. Which is pretty disastrous because he needs that letter for other things. He missed a couple of appointments once because he forgot and once because he was put off going because couldn’t find the letter. I had to ring and get him back on their books because they have a two strikes and you are out rule (pretty common with NHS dentists). I had to explain he was a vulnerable adult. A10 minute appointment not really enough for someone who needs more time to gather their thoughts or who is very anxious about treatment. His teeth not in good shape because of his diabetes and years of not having a dentist so exactly the sort of person who needs regular check ups but they only use mobile phone reminders which is no good for him as he is always losing them. He was never offered an alternative communication. No mention of a community dentist or special care dentist. For him what mattered most was that dentist was on a bus route so easy for him to get to and from. No joined up thinking between Adult Mental Health Team (legally responsible for his primary health care needs) and or his GP – both whom could have referred him to the community dentist. I checked online when I heard about this focus group and found the Oxfordshire Service easily online with a clear explanation of what they provided and how to get referred to them."

## Q5: What 3 things are important when you are at the dentist?

- Physical access needs are met e.g. they know how to guide a visually impaired person.

- Communication access needs are met e.g. explanations in plain English.

- Information e.g. how long I will be waiting before I am called.

- Efficiency e.g. prompt and reassuring approach.

- Flexibility. if I need some treatment they do it at the same appointment so I do not need to visit again.

- Professional e.g. they are good at dentistry.

- Compassionate and kind e.g. take their time and talk to me respectively.

- Listens to me e.g. recognises that I know best about my health and access needs.

**"communication skills, I need them to be deaf aware because I am hard of hearing, I need eye contact and visual clues, I need people to take their time. I need them not to get frustrated with me."**

## Q6: What stops you going to the dentist?

- Physical access barriers.

- Inaccessible appointment reminders.

- Inflexible appointment times.

- Not being recognised as an expert in my own health condition.

- Financial hardship, there was little awareness that you can get help with dental costs if you are on a low income.

- Travel, some people would not travel far to visit a dentist, others said they would. A general observation is that people with several health conditions and/or impairments would be willing to travel if their multiple access needs would be met.

**"no I wouldn’t travel. I would rather stick with my dentist."**

**"the fact that they could accommodate my extra support needs is the most important. I would travel, up to 50 miles."**

**"why can’t dentist be mobile, come to where the patient is? Or have a rota of general dental practices who host a special care dentist."**

Suggestion: Disabled people and other people from diverse communities should have a 'Primary Health Profile or Checklist' that all primary care providers could review. It could include access needs, information about help with costs for charged for services and signposting to other specialist services.

## Q7: Do you know about special care dentists?

- Nobody had heard of special care dentists.

## Q8: What would be a good name for a special care dentist?

- additional care dentist.

- personal plan dentist.

- Special Care Dentist.

- Community Care Dentist.

- accessible care dentist.

- For people who need additional support.

- a dentist that can support everyone’s needs.

## Q9: Anything else?

- Ensure more NHS dental practices are better at being accessible and inclusive. This is more than physical access, this is also about attitudes, communication and understanding.

- The requirement to make reasonable adjustments should be included in contracts and inspections.

- CQC ratings should be made more prominent for patients.