UK-based specialist dental professionals' experience of working with autistic patients

McMillion, Audrey,[1] Beth Tobiansky,[1] Kefei Wang,[1] Cronin, Aaron J,[4] Johnson, Adele,[2] Monteiro, Joana,[3] & Remington, Anna[1*]

[1]Deparatment of Psychology and Human Development, UCL Institute of Education
55-59 Gordon Square
London WC1H 0NU

[2]Royal National ENT & Eastman Dental Hospital
47-49 Huntley St
London WC1E 6DG

[3]Great Ormond Street Hospital
Great Ormond St
London WC1N 3JH

[4]Barts Health NHS Trust, The Royal London Hospital
The Royal Hospital, Whitechapel Rd
London E1 1BB

*a.remington@ucl.ac.uk
Director, Centre for Research in Autism and Education
UCL Institute of Education, University College London
55-59 Gordon Square
London WC1H 0NU

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Abstract

Aims: Previous research has demonstrated that autistic individuals often experience difficulties accessing dental care, both as a result of autism specific difficulties and practitioners' attitudes towards autism. However, very little research exists that explores dental professionals' experiences of providing care to their autistic patients. The aim of this study was to investigate the strategies UK-based dental professionals' use when working with autistic patients. **Methods and Results:** In this study, dental professionals (n=16) from a variety of specialty roles (special care, paediatrics, orthodontics) were interviewed. We asked participants to talk through, in depth, specific cases they had encountered in their practice, what sorts of accommodations they had provided, and what concerns had arisen during appointments. Thematic analysis was used to analyse the data and revealed four main themes: the unique dental needs associated with being autistic, effective adaptations to practice, the crucial role of the caregiver, and the importance of specialist knowledge. **Conclusion:** Recommendations for how dentists can improve the dental experiences of autistic patients can be drawn from the specialist dentists' responses in this study. These include involving autistic patients in decisions about their treatment and being flexible and willing to work with autistic patients and their caregivers.

Keywords: specialist dentists; autism; paediatric dentistry; special care

A note on terminology: Many autistic people and their allies prefer identity-first language (e.g autistic person) to person-first language (e.g person with autism).[1] As such, this paper will use primarily identity-first language.

Introduction

Autism is a developmental condition experienced by over 1% of the UK population[2,3] characterised by difficulties with social communication and interaction as well as restricted and repetitive behaviours, including sensory sensitivities.[4] These core aspects of the condition can act as barriers to accessing dental care, with studies finding that autistic individuals have more unmet dental needs and greater difficulty accessing dental care than non-autistic individuals.[5, 6, 7] For example, communication difficulties can be a significant barrier to dental treatment[8, 9, 10] as the inability to establish effective communication with dental professionals can mean that individuals are unable to express their needs.[11, 12, 13, 14] Sensory sensitivities can also be particularly problematic in the dental surgery, where there are often loud noises, bright lights and unfamiliar tastes and smells.[9, 15, 16, 17] Unsurprisingly, this can result in uncooperative behaviour and impact the ability to undergo dental treatment.[18] One study suggests that the proportion of autistic children with unmet dental needs is approximately 8–12% compared to approximately 5% of their non-autistic peers.[19]

Associated difficulties can also affect dental care provision for autistic people. One of the most common co-occurring conditions is anxiety,[20] with the lifetime adult prevalence for autistic individuals thought to be 42%, higher than the reported 27% within the general population.[21, 22, 23] Though many people find visiting the dentist an anxiety-inducing process,[24] it may be disproportionately stressful and demanding for autistic individuals and their families.[16] Indeed, in Sweden and the UK, autistic adults report higher levels of dental anxiety than non-autistic adults.[25, 26]

One factor suggested to be crucial in promoting better access to successful dental care for autistic people is the approach of dental professionals. Dental professionals play an important role in establishing effective communication with and listening to parents and patients, recognizing the unique needs of the individual, and having flexibility to

accommodate these needs.[13, 18, 27, 28] Research from the USA and the Netherlands has highlighted that parents of autistic children struggle to find dental practitioners willing to treat their children at all.[5, 29] The rates of acceptance are particularly low for those on the autistic spectrum: when asked, dentists in the US report being most reluctant to treat autistic adults compared to other patient groups with additional needs.[30] Alarmingly, only 33% of the practitioners surveyed responded that they would be willing to treat autistic adults, and only 40.1% indicated that they were willing to treat autistic children.

There is a scarcity of dental providers who are specifically trained and therefore many may not feel competent to work with autistic patients in the UK. According to the General Dental Council 2017 annual report there were around 111,212 registered dentists and dental care professionals (dental nurses, clinical dental technicians, dental hygienists, dental technicians, dental therapists and orthodontic therapists) in the UK.[31] Of these, 4,355 were registered as specialist dentists (not including nurses, technicians, and hygienists), with only 7% of these specialists working in special care dentistry and only 6% in paediatric dentistry. Whilst autistic patients are treated in a variety of dental settings, including general practice, community and hospitals, as well as by general and specialist dentists, there is currently limited specialist care available in primary care settings, with the main focus being on community dental services.[32, 33]

A recent survey of over 350 dental professionals (of these almost 19% were general practitioners and 36.1% worked in a general practice) revealed that many had high levels of knowledge about characteristics of autism and were eager to adapt their practice to better suit autistic patients.[34] However, many reported lower levels of confidence and a desire for more training and information on how to modify treatment to ease discomfort experienced by autistic people in dental care settings.[34]

By interviewing dental practitioners (predominantly special care, orthodontists, and paediatric dentists) who have experience working with autistic people, the aim of this study was to investigate techniques currently being used to support autistic patients. We hypothesised that these practitioners are using a variety of modified approaches in order to improve dental care outcomes for their autistic patients. Through showcasing examples of best practice and recommending approaches that can be employed to maximise success when working with autistic patients, we hope that this study can help all dental professionals feel confident in their ability to ensure that the dental needs of all autistic patients are met.

Materials and methods

Sixteen UK-based dental professionals (12 female, 4 male) took part in the current study and were recruited via convenience sampling following their participation in our previous research. Participants received written information about the study prior to volunteering, and gave both verbal and written consent before the interviews.

Ethical approval was given via [blinded for review]. Participants took part in semi-structured interviews, lasting approximately 25 minutes, conducted via Skype voice call. Interviews were audio recorded and transcribed verbatim by author KW. Interview questions covered dental professionals' experience working with autistic patients and their knowledge and training regarding autism. Particular focus was placed on any barriers which arose during treatment, and modifications made to overcome them. The interview schedule can be found in Appendix A. All participants gave written consent prior to participating, and were informed that they could choose not to answer any specific question, or discontinue at any point, without needing to give a reason.

Data analysis

Transcripts were entered into NVivo 12 (2018) and thematic analysis[35] using an inductive approach was used to analyse the data. Two authors (BT and AR) independently familiarised themselves with the data before devising provisional codes. Codes were then organised into preliminary themes. Authors discussed and reviewed themes on several occasions before agreeing on final themes and subthemes.

Results

Participants ranged in age, dental speciality and role (paediatric dentist, special care dentist, dental nurse, orthodontist and dental therapist), location within the UK, and number of years in practice (See Table 1 for full demographics). All had experience working with autistic patients, 50% had a personal connection to autism (e.g. had an autistic family member) and 69% had received some autism training.

Table 1. *Participant demographics, n=16*

Characteristic	*n (%)**	Characteristic	*n (%)**
Age		**Role**	
Mean: years (SD)	44.25 (12.18)	Paediatric Dentist	5 (31.3)
Range: years	25 - 62	Special Care Dentist	3 (18.8)
Sex		Dental Nurse	3 (18.8)
Male	4 (25.0)	Orthodontist	4 (25.0)
Female	12 (75.0)	Dental Therapist	1 (6.3)
Years in practice as a dental professional		**Practice**	
Mean: years (SD)	21.81 (12.49)	General Practice	1 (6.3)
Range: years	4 - 45	Community Practice	7 (43.8)
Location of dental practice		Hospital	3 (18.8)
North East	1 (6.3)	Other	5 (31.3)
Yorkshire and The Humber	2 (12.5)	**Received specific autism training**	
East Midlands	2 (12.5)	Yes, a specific session	4 (25.0)
London	2 (12.5)	Yes, part of a broader session	7 (43.8)
South East	5 (31.3)	No	5 (31.3)
South West	2 (12.5)	**Personal experience of autism**	
Scotland	2 (12.5)	Yes	8 (50.0)
Sector of work		No	8 (50.0)
NHS provision	10 (62.5)		
Mixed (NHS and private practice)	6 (37.5)		

**Unless otherwise specified*

SD = standard deviation.

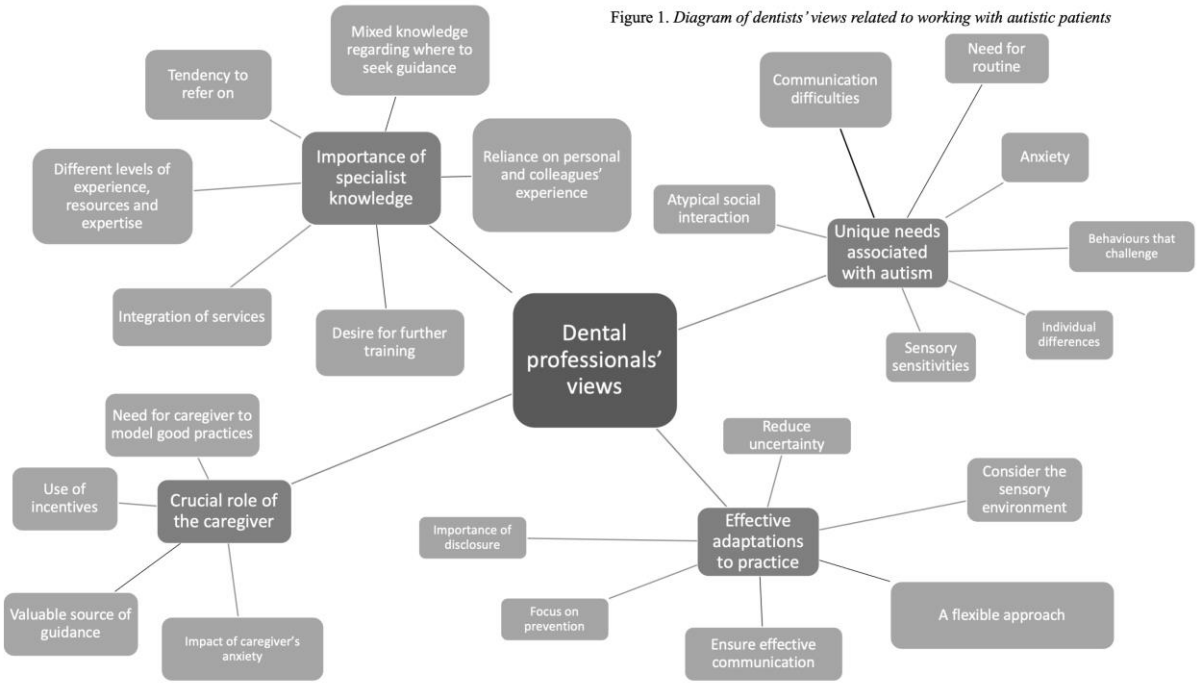
Specific session = Examples included autism awareness training and Makaton training

Broader session = Examples included special needs training as an undergraduate, post graduate and whilst working

From the interviews, four main themes were identified: (1) Unique needs associated with autism; (2) Effective adaptations to practice; (3) Crucial role of the caregiver; (4)

Importance of specialist knowledge. Figure 1 includes a diagram of themes and sub-themes, and the quotations included in the following section represent these. Additional supporting quotations can be found in Appendix B. Quotes are attributed to dental professionals using the codes DP1-DP16 to maintain anonymity but show the spread of responses.

Figure 1. *Diagram of dentists' views related to working with autistic patients*



Unique needs associated with autism

Participants recognised a number of unique needs associated with autism impacting the care given. *Atypical social interaction* (including lack of eye contact and engagement) was mentioned: 'he wouldn't look at me, wouldn't engage with me, he wouldn't let me examine him whatsoever' (DP3). Participants also noted that some autistic patients had *communication difficulties*, including lack of verbal communication and difficulty expressing themselves: 'they seem to understand what we're asking them to do, but they seem to have trouble letting us know what they're feeling about and things like that' (DP12).

Some practitioners commented on their autistic patients' *need for routine*, and the care they took to adhere to this on each visit to avoid distress and refusal of treatment:

> *He basically didn't have "his cup" with "his juice", therefore he wouldn't take the pre-med, and we had to abandon the general anaesthetic for that day… … it really impressed on us the importance with severely autistic children of making sure that you're fully aware of any normal habits that they have, and making sure that you stick with their routine (DP3).*

Those we spoke to highlighted that many of their autistic patients also displayed a number of *sensory sensitivities*: 'It could be that they're very hypersensitive to touch, taste, smells, textures' (DP7). Areas where this was particularly problematic included the waiting room, use of strong flavoured toothpaste or fluoride varnish, wearing light protecting sunglasses, using the drill and touching the patients' face during examinations. In some cases, participants talked about their autistic patients displaying *behaviours that challenged*, such as dramatic shifts in behaviour: 'very very calm... …unless he's unhappy and then he really shouts and jumps and throws himself on the floor' (DP1). However, it was noted that some autistic patients were able to self-soothe in certain situations.

One of the most commonly remarked upon challenges was *anxiety.* Participants commented that many autistic patients were extremely anxious, which in some cases caused a reluctance to be treated. Some thought the root of this anxiety was unfamiliarity, however given that dental anxiety is fairly common, they questioned whether this anxiety was more than that displayed by their non-autistic patients.

While commonalities were identified across the various needs and challenges discussed, the dental professionals recognised the *individual differences* of their patients. Participants also highlighted that they worked with a very diverse sample, with patients varying in age, severity of support needs and co-occurring conditions: 'So it's the whole

spectrum and everything in-between that we manage' (DP7). As such, participants were aware that preferences and challenges were unique to each patient.

Effective adaptations to practice

Participants spoke about the need for *a flexible approach* to address any challenges encountered: 'one of the things that overcomes the barriers are the dental staff's willingness and ability to be flexible and accommodate the child' (DP11). This often involved changing aspects of the dental professionals' practice. These changes were made very willingly, with participants showing positive attitudes towards their autistic patients: 'It's lovely to treat them and be part of their world …and when something works it's like such a joy' (DP15). Specifically, several participants spoke of changing the location of the examination or modifying their choice of dental treatment plan. In some cases, this meant using simplified procedures to ease autistic patients in, as well as lowering expectations. Some participants also noted times where they had needed to change or stop the course of treatment altogether. Some also felt there was an increased likelihood of general anaesthesia use for their autistic patients. However, the risk of general anaesthesia was acknowledged by many participants, and professionals across disciplines worked together to carry out multiple procedures (including blood tests, dental work etc.) under the same general anaesthesia.

Participants felt that many of the adjustments they made were in order to *reduce uncertainty* and resulting anxiety, including increased time in appointments, slower treatment and acclimatisation visits:

> *For a significant proportion of my children who have an autism diagnosis, it may take them a little bit longer, or significantly longer to attain, what I call dental life skills like, being able to enter the surgery, being able to sit in a chair, allow a dental exam, accept*

> *a toothbrush, accept fluoride varnish, accept air water suction and be able to understand why they're there and what's involved, put glasses on, put a bib on, and make that a normal part of their dental experience (DP7).*

> *They go in and they desensitise themselves to the surgery and they get a shot in the chair, put the glasses on, put the bibs on, have their teeth brushed. Familiarise themselves with the mirror and we give them, a consistent routine when they came into the surgery, so they know what to expect (DP7).*

Additionally, participants commented on using social stories, short descriptions of activities (in this case going to the dentist) and what to expect as well as using the Picture Exchange Communication System (PECS), which uses pictures to enable communication. Lastly, another way to reduce uncertainty mentioned by participants was establishing a set routine with autistic patients. This included keeping the day and time of appointments consistent across visits, and ensuring that everything ran to time.

The importance of *considering the sensory environment* of their surgeries was highlighted. This included creating a calm, relaxed environment by allowing music, headphones and iPads and modifying light levels: 'In some of the surgeries… we can use you know the dimmer switches to keep things a bit more tranquil and not as bright and harsh for them' (DP16). Some participants were able to provide special quiet clinics, but this was dependent on constraints on resources. Sensory aspects of dental products were also considered by participants. Desensitisation and acclimatisation were utilised to get autistic patients accustomed to tastes and textures in a slow, measured manner: 'We're particularly careful from the desensitising and acclimatising to fluoride varnish. It's got a strong colour,

taste, texture, smell, so we're quite careful there' (DP7). Using unflavoured toothpaste, such as Oranurse, was also found to be useful.

Further to making procedural changes, participants also discussed the importance of *ensuring effective communication.* This included making sure they used clear, unambiguous explanations, and in some cases Makaton (using signs and symbols to support spoken language) to ensure the autistic patient understood what they were doing. A further technique used by some participants was using autistic patients' interests to engage them and increase rapport and compliance. Open communication was also mentioned with respect to *the importance of disclosure* of an autism diagnosis. Participants stressed how vital it was to know about patients' needs before treatment began in order for individualised care plans to be put in place. In many cases, those we spoke to found that diagnoses were stated on the medical history included with the referral. When this was not the case, participants' confidence in their ability to detect autism varied.

In recognition of these modifications and the fact that dental care can be more difficult for this population, participants recommended a greater effort be placed on *prevention and early intervention* to reduce the amount of dental work needed later. For instance, one practitioner was able to carry out prevention programmes in additional support needs schools: 'we provide prevention and tooth brushing programs and fluoride varnish programs for our ASN schools, that's an additional support needs schools. There's a high ratio of children who have autism who attained these skills' (DP7).

Crucial role of the caregiver

Participants mentioned that the majority of their autistic patients (predominantly children but also adults) were accompanied to appointments by a parent, carer or family member. On the whole, participants viewed parents as *valuable sources of guidance*, helping

to inform the aforementioned adaptations: ‘you just have to listen carefully to what parents say to you. I think we are getting quite a lot of clues from parents as to what the best way is to go about treating patients with autism’ (DP9). Some participants noted that parents sometimes implemented their own techniques to aid treatment, such as the *use of incentives* to encourage their children to cooperate: ‘There was another one that…he's got to have a huge gift… he doesn't get it until he's allowed us to have a look in his mouth’ (DP12).

Overall, participants felt that caregiver support was crucial for facilitating some adaptations (for example social stories) and improving the basic dental skills of their patients, and so highlighted the *need for caregivers to model good practices*. However, participants found that parents varied in their level of support*:*

> *Any parent or carer, they can vary, and you have someone very supportive, and will really sort of push you to get the best for their child or person that they’re caring for but, others who aren't so helpful and might not persevere with the brushing, persevere with bringing them to the dental surgery so, lots of variation. Well, that's not the right word but other people that support and people who don't necessarily give as much support, and some are excellent (DP8).*

Participants noted the *impact of caregiver’s anxiety* on their child, with one participant noting: ‘mum herself was quite anxious about dental treatment, and we know that will offset, if you've got an anxious parent, it makes the child anxious’ (DP13). Thus, parents had the potential to hinder elements of the dental visit, as their anxiety and misinformation in some cases became a barrier to treatment or meant that it was necessary for participants to provide support for parents, managing their expectations and being attentive to their needs.

The importance of specialist knowledge

In many cases, participants learned 'on-the-job' *(DP6), relying on personal and colleague's experience* to become better skilled:

> *An awful lot of it, I've learnt by doing. You know, just by having encountered lots of patients in the autistic spectrum, you get the experience of "this worked before, we'll try this… we know this doesn't work". That sort of thing. And you start to recognize patterns in the patients, things you've encountered before (DP4).*

Encouragingly, participants suggested that there was perhaps a recent shift to include more degree level training, with younger participants commenting that there were courses available to them at university. Those without satisfactory training expressed a wish learn more. However, participants showed *mixed knowledge regarding where to seek additional information and training*; many were aware of a number of resources for help and more information, but this was not universal.

There was a clear *desire amongst participants for more formal autism training*. 'on my PDP [Personal Development Plan] the other day, I said are there any courses within the community that deal with autism that I can go on. Because I'd like…to know a lot more about it' (DP12). The level of training received by participants tended to be dependent on specialty:

> *I think, because I'm in special care they [dental nurses] have a lot of experience in, working with patients with autism, but…we do receive some training so I think because of where I'm working, they are trained but maybe in general practice, they might not be (DP8).*

Participants spoke about the clear distinctions between community, paediatric and special care dental practitioners and how these specialists often had *different levels of experience, resources and expertise,* and were therefore better equipped to treat autistic patients than high street and general practitioners. This meant that they often saw patients referred from general dentists:

> *There's a huge difference and so…most autistic children go to the salaried community dental services so, if you ask a nurse from the community dental services, then they will know…a lot more about autism than a nurse from the high street (DP11).*
> *A lot of the children who come for repeated appointments… they're referred in to us and they're not sent back to their own dentist because they wouldn't get the treatment that we can provide for them, the kind that they need (DP12).*

According to participants, this included the crucial capacity to take extra time where necessary as well as less pressure for high patient turnover. This led to some of their autistic patients travelling long distances to access these specialist services.

Participants questioned whether the *tendency to refer* was always justified. In several cases, referrals were made just on the basis of an autism diagnosis: ‘sometimes people see the diagnosis and think, or just read it on the medical history form, and just think “Oh that’s going to be a bit difficult. Let’s move it on”’ (DP4). Some participants felt that this was contributing to an overburdening of specialist services, using up valuable resources that should be reserved for the most disabled patients.

However, despite this, there also seemed to be *integration of services* through various care teams, in order to maximise outcomes for their autistic patients, and, in some cases, participants were able to discharge patients back to high stree dentists:

> *We liaise and work closely with our colleagues who work in tertiary care, our consultants in paediatric dentistry, so, we'll get a very good strong network and we've got a good working relationship with our general dental practitioner colleagues as well. So, actually for some children we'll do a shared care agreement where, they'll remain registered with their own general dental practitioner but we might provide certain aspects of a child's dental care, maybe the fissure sealants or, desensitize them to fluoride varnish, and then just maybe seeing them yearly, but the dentist who they regularly, who they're registered with, they would see on a more regular basis (DP7).*

Discussion

This study is, to our knowledge, the first UK-based study to use qualitative analysis to provide an in-depth look at specialist dental professionals' experiences of working with autistic patients. When interviewed, these dental professionals discussed unique needs associated with autism, which could present challenges to dental care. These included core characteristics of autism (e.g. sensory sensitivities, communication barriers, and resistance to change) and associated difficulties such as increased levels of anxiety. Consequently, our participants indicated a need for accommodations to ensure effective dental care for their autistic patients. Participating dentists also expressed concerns about what should be done when a patient is unable to cope with treatment. They felt it was important to prevent overuse or repeated uses of general anaesthesia, as increased time under anaesthesia for procedures with multiple steps like crowns, bridges, and orthodontics was not in the patient's best interest and could present risks, meaning that simplified treatments (that do not require general anaesthesia) may be preferable. Participants also emphasised the importance of caregiver involvement and dental training when approaching any concerns and improving their practice.

When considering their own experience of successful adaptations, the dental professionals we spoke to reported the importance of taking a flexible approach, minimising uncertainty, considering the sensory environment and ensuring effective communication (including about the patient's diagnosis). They recognised, however, that the diverse nature of the dental sector, restricted time and need for high patient turnover rate due to NHS targets meant that such changes were not always achievable, especially for general dental pracitioners.[16]

As well as commenting on the commonalities between their autistic patients, participants indicated that they were very aware of their patients' individual differences, creating a unique profile of needs specific for each patient. Such findings were congruent with those identified in current literature on autism and dentistry.[7, 8, 9, 14, 15, 16, 36] Dentists recognised that even as they have a wide variety of approaches at their disposal, every autistic person is different: 'basically, we're treating the child as an individual and trying to…meet their needs' (DP7). Thus, in line with participants' responses and previous research, we recommend that each individual be included in decisions about their dental health and wellbeing and the supports they prefer for their dental appointments. Further, caregivers should also be involved in decision making, as they, on the whole, were a valuable learning resource for participants (e.g. implementing incentives as a technique to aid treatment cooperation). This supports findings highlighting the importance of effective communication between parents and professionals.[8, 13, 37, 38]

However, the opinions of autistic people and dentists differed on a few significant points. For instance, in a recent study of autistic people's dental experiences in the UK, autistic adults did not mention a need for caregivers to attend the appointment with them, as mentioned here, and autistic individuals expressed that their anxiety stemmed from known (mainly sensory) concerns rather than concerns about the unknown as dentists speculated in the current study.[26] Further, dentists in the current study recommended using strategies (like

incentives) that autistic adults did not mention in the previous study.[26] These variations in opinion highlight the importance of including patient voice when seeking to understand and ameliorate challenges encountered. Some of these discrepancies, however, may be due to differences in approaches for autistic children versus autistic adults. For example, it may be legally required for parents or carers to be present while children are being treated. In the UK, a young person is presumed to be capable of giving consent for treatment at 16 years of age. Younger children may give consent considering their maturity and ability to understand the treatment (Gillick competence). In the present study, we did not ask participants to specify whether the adaptation or technique they mentioned was for adults or children, however many shared their experiences working with a paediatric population. As such, the findings may highlight the need for dentists to take different approaches when working with autistic adults compared to autistic children. To explore this further, future research should seek autistic children's views about their preferences at a dental appointment, and dentists' views on specific treatment approaches for autistic adults compared to autistic children.

Unfortunately, both autistic patients and dentists acknowleged that varying standards of care are provided across dental practices. In addition to the dental setting, previous studies of dentists and GPs have indicated that practitioners with personal knowledge of autism may have higher levels of confidence in treating autistic patients.[34, 39] Our participants claimed an increased knowledge based on their practical, 'on-the-job' experience, and indicated that all dentists should learn more about autistic people from autistic people.

There is also a need for training to complement applied knowledge. Participants in this study expressed a desire for autism training beyond that which they had already received (see table 1). This suggests that the current broader special needs dental curriculum (at both an undergraduate and postgraduate level) does not cover autism in sufficient detail. Encouragingly, NIH guidelines,[40] nurse training[34] and recent changes to degree level courses

are beginning to call for more autism specific training. The next steps may be to increase general dentists' access to information about working with autistic patients and to conduct specialised teaching to overcome specific difficulties, such as preparing for sensory sensitivities,[16] as well as focusing on the continuous education of professionals.[29] Theoretical and on-the-job training can help to increase the confidence of healthcare professionals (including dental professionals)[34] in their ability to work with autistic patients.[40, 41] Further, it would be helpful to create specialist posts in primary care to treat patients and support general dentists in doing so appropriately. Adequately formed Managed Clinical Networks are crucial in identifying this gap and creating structures for appropriate clinical mix, support and seemless patient pathway progression. When considering this increased emphasis on providing general dentists with specialist knowledge, it will also be crucial to establish autistic patients' preferences regarding where to access their dental care (e.g., high street practices vs. special care settings).

As our participants indicated a mixed understanding of where to seek further help, professionals should be made aware of the growing number of resources and best practice guides that are available (for example from the National Autistic Societyand British Society of Paediatric Dentistry).[42, 43, 44] Increasing professionals' self-efficacy and confidence can lead to them working with more autistic patients[9, 10] and may help reduce referrals based solely on diagnosis. Further, such issues are not unique to the dental environment, with research exploring autism related challenges in general healthcare professions (for example, general practitioner and psychiatrist) concluding much the same.[37, 39, 41, 45] As such, making courses available to all healthcare professionals who desire further training, not only those in more specialised services, is crucial. Additionally, a national champion for dentistry and autism could be appointed, similar to the clinical champion for autism to the Royal College of General Practitioners (RCGP), who helps develop learning and educational resources as well

as help the RCGP to promote models of best practice.[46] Such a scheme may be beneficial for the large dental bodies to help practitioners implement more difficult adaptations. This champion could also promote the importance of prevention and early intervention to minimise the amount of invasive treatment needed, and consequently the amount of adaptations. Programmes already exist where community dental services provide support to special education schools, but expansion of these partnerships could promote the inclusion of dental hygiene practices as part of an individual's routine dental care.

The findings reported here offer guidance regarding best-practice in working with autistic patients. However, the limitations of the study must also be acknowledged. With only 16 participants who primarily worked with paediatric patients, this was a relatively small sample centered in London and the southeast so not all dentist experiences and expertise were captured in our sample. Despite this, the depth of interview responses provided a diverse knowledge set from expert specialist dental practitioners. It would be informative (especially around such issues as referrals based on diagnosis) for future studies to qualitatively explore the experiences of general dentists working with autistic patients. Additionally, half of the participants had a personal connection to autism, which may suggest a response bias toward more understanding of autistic patients and reporting of more attentive practices for autistic individuals than in the general population of dentists. Despite this, findings align with current literature encompassing parents', practitioners' and some autistic individuals' perspectives, from a range of cultures.[8, 9, 13, 28, 35] This suggests that the core challenges and adaptations when supporting autistic patients are relatively standardised, and that the themes identified encapsulated dental professionals' experiences of working with autistic patients. Therefore, these results could be used to inform the development of best practice guidelines for both specialist and general dental practitioners.

Conclusion

To conclude, dental professionals experience a number of barriers when working with autistic patients, but they have developed many effective techniques to overcome them. The ability to implement these techniques is dependent on one's level of training, specialty and caregiver support. Above all else, recognising that each autistic person is unique and has their own individualised needs is fundamental for the provision of effective care. Understanding the experiences of dental professionals can help improve access to dental care and address the unmet needs of autistic patients. Several recommendations from this study emerged based on the results. Dental professionals should include the autistic patient in decision making about their treatment plan whenever possible. Additionally, dental professionals should be willing to flexibly modify these plans as care continues. All dental professionals should have access to basic training about special care dentistry and autism at an undergraduate level, with specific hands-on training available for those who wish to avail themselves of it. Dentists should always be willing to work with autistic patients and their caregivers (who can provide valuable information and aid in treatment) and should be mindful of making secondary care referrals based solely on a diagnosis of autism.

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Appendix A

Interview – Dental Professionals

Part 1: About you

1. **How many years have you been in practice?** _____

2. **What is your area of dental practice?**
   ☐ General Dental Practitioner ☐ Paediatric Dentist ☐ Special Care Dentist
   ☐ Dental Nurse ☐ Hygienist ☐ Orthodontist
   ☐ Other (please specify) _____

3. **In what setting do you practice?**

   ☐ Community ☐ Hospital ☐ Teaching Hospital ☐ Both

4. **Do you work in private practice or NHS provision? (tick all that apply)**

   ☐ Private ☐ NHS ☐ Mixed

5. **Do you have personal experience of autism?** (E.g. through being autistic yourself, or through having a relative, colleague or friend on the autism spectrum.)

   ☐ No ☐ Yes (please specify) _____

6. **Have you received specific training about autism? (if yes, have you found it helpful during treatment?)**

Part 2: In Practice

1. Could you tell us about times where you have encountered autism in your practice?

- How many autistic patients have you knowingly treated? (If many, what types of cases (e.g. routine check-ups, planned treatments, emergency treatments?)

- Let's talk through one case in detail but feel free to mention any relevant examples from other cases as we discuss different aspects.

For each case:

- When was this?
- What kind of case? (routine check-ups, planned treatments, emergency treatments/child or adult)
- Was the patient accompanied to the appointment?

- How did you know your patient was autistic? (and at what point?)
    - If they noticed: then how confident were they that they were correct?
    - If they were told: would they have detected it themselves if not told?
- Did any issues arise from the fact that the individual was autistic?
    - If no: That's great. Sometimes there can be issues that arise with autism. Why do you think this this particular case went well?
    - Did you make adjustments in order to avoid known issues?
    - If there were difficulties: Did you make any adjustments to your normal procedures to accommodate these issues?

- [if no issues and no adjustments] That's brilliant. I'd now like briefly talk through a few aspects of autistic behaviour that are sometimes evident, to see whether they were present but didn't cause difficulties, or whether they were not seen at all.
- [If an issue/adjustment was raised] Every autistic person is different, and you identified X as being an issue, but I'd just like to talk through a few other issues that can arise to see whether you experienced any of them as well.

    a) Some autistic people find social interaction challenging. Was this something you noticed in this case?
    b) Some autistic people have communication difficulties (e.g. expressing their wishes, understanding your instructions or explanations): did you find that to be the case?
    c) Some autistic people don't like deviating from their normal daily routine and may show repetitive behaviours (e.g. hand flapping, rocking). Did you notice this?
    d) Some autistic people have sensory sensitivities (e.g. don't like bright lights, background noise etc). Was any of this evident in this case?
    e) Autistic people often have high levels of anxiety. Did you find this to be the case?

- Do you think any of the issues we've talked about affected the care given?

- Was there any additional support/resources that would have been helpful to you in this case? If so, what was it?

Question Time and Wrapping Up

- Is there anything else you would like to mention or add?

- Is there anything you would like to ask me about the project or anything that has come up today?

Appendix B

Themes and subthemes from dental professional (participant) interviews, with illustrative quotes.

Themes	Sub-themes	Participant Quotes
1. Unique needs associated with autism	*a) Atypical social interaction*	'they don't always smile very much or, say thank you for appointments or you know, it's, they just, it's almost like they just sort of sit there and have the treatment done, then walk out, they don't really kind of interact with you at all' (DP10) 'he walks into the room and he walks straight over to the corner of the room, faced the corner of the room. And he wouldn't look at me, wouldn't engage with me, he wouldn't let me examine him whatsoever' (DP3).
	b) Communication difficulties	'sometimes they can't communicate verbally so that adds a whole different level of issues onto how to communicate with them effectively' (DP3) 'They seem to have trouble… telling us what they want rather than, they seem to understand what we're asking them to do, but they seem to have trouble letting us know what they're feeling about and things like that' (DP12).
	c) Need for routine	'The only thing is, again they don't like change. So, I think that there was one, when I was not there and he had to see someone else, and he said he wouldn't sit in the chair' (DP5) 'On the day of his general anaesthetic we realized that he needed to have a pre-med, and he basically didn't have "his cup" with "his juice", therefore he wouldn't take the pre-med, and we have to abandon the general anaesthetic for that day and bring him back on another day. So it really impressed on us the importance with severely autistic children of making sure that you're fully aware of any of any normal habits that they have, and making sure that you stick with their routine where it's really important for them' (DP3).
	d) Sensory sensitivities	'some of them they are very oral sensitive. So, to put your fingers in their mouth or instrument in their mouth, it takes a very long time to desensitize them.' (DP15)

		‘It could be that they're very hypersensitive to a touch, taste, smells, textures’ (DP7).
	e) Anxiety	‘But he was very dental phobic, and he wouldn’t, he got really anxious having treatment and he required some restorations. So, I, I saw him regularly, he’d gotten used to seeing me. And then, I, for the actual treatment we actually had to put, he was about 18 I believe. we had to provide him with some oral diazepam to, so he was happy to come for the surgery … or they may be very anxious and unsettled and, sort of not want to sit in the dental chair and sort of be moving around or running around’(DP8) ‘I think his altered behaviours were probably also driven by a bit of an anxiety, whether that was purely just dental anxiety whether that was general anxiety, it was difficult to differentiate’ (DP13) ‘In the last year we've had three children that have refused point blank to walking to the clinical space because they're too scared by it and because they are used to their own general dentist. But we are completely fresh faces; it's a different environment, it's a different set... you know, even the colours are different, and it smells different’ (DP2).
	f) Behaviours that challenge	‘I had to calm him down and then, we started treatment subsequently and he did very well and he's been fine, he's been very compliant and very good. We had some issues with behaviour at the beginning’ (DP10) ‘I mean this one, we had one young man, referred in and is... very severely autistic and it's very very calm, unless he's sort of ... unless he’s unhappy and then he really shouts and jumps and throws himself on the floor and things. So you know he goes from being really calm and passive and friendly to quite extreme behaviour, you know... very, very quickly’ (DP1).

	g) Individual differences	'What we notice very clearly is that whether you have an autism diagnosis or not, is that every child is different and an individual and what we try to do is to focus in on every child as an individual and identify what their particular needs are, so we can, tailor how we manage them, how we modify our communication, how we modify what we do in the surgery to, facilitate their care to suit them best … So, we use a variety of techniques, but basically, we're treating the child as an individual and trying to interact and meet their needs that suit them best' (DP7) 'If you've got, you know a hundred different patients, you might need a hundred different ways of trying to get them to cooperate. certainly not one size fits all' (DP1) 'So it's the whole spectrum and everything in-between that we manage' (DP7).
2. Effective adaptations to practice	*a) A flexible approach*	'If they don't want to sit in the chair, we don't force that, they might want to sit on their mom, they might want to stand in the corner, they might want to be on the floor, we get down on the floor to examine them, that's not a problem for us, unless you get to my age in which case it can be bit of a problem **laughs**' (DP12) I have to adjust to what they are comfortable with. So, if somebody's comfortable to be examined on the floor, they are having a floor examination. If somebody's happy to be examined on the chair, they are having a chair examination. and then we move from that (DP15). 'These aren't naughty children, these are children that don't understand what's going on round about them, you know and you've got to always remember that.' (DP12) It's lovely to treat them and be part of their world …well for me, I don't know if it's for

		everybody else. But for me it is…and when something works it's like such a joy' (DP15). 'Some of the children they enter the surgery, and they want to use the buttons on the chair. It's an intense like for them to be able to control the chair, so we use that to our advantage and we say like "sit in the chair, glasses on, bib on, get the chair into the position for me." For some children that maybe they want water from the tap that gives them a sense of calm. So… I say "right ok, let me have a look in your mouth. I'll count to ten or to 20, then I'll stop, and then you can get a break" and allow them to calm themselves using you know the water, or something' (DP7) 'he's a bit of a computer whiz, he's really, really interested in the computer side of things. so he was allowed to, when his appointment's finished, he puts in what we want for the next appointment, so there's a drop-down box and it's sort of , you know, a difference between "adjust fixed" or "adjust removable" appliance, that kind of thing. So he runs that in, and then he puts down how many weeks it is before he's got to be seen again, and then he sends it out and that sort of thing' (DP2) They seem to get fixed on one particular thing that they like and it's really important for us to find out what that is and if we can, you know put it into the treatment you know into that visit, then they are happy (DP12). 'I think for the patients at the severe end of the autistic spectrum, there are constraints on the treatment you can offer them, especially if you're going to have to treat them under general anaesthetic. Because you don't want to have lots of repeat general anaesthetics, and it tends to mean that the treatment you can offer them inevitably becomes simpler. But you're not going to be able to offer somebody crowns, and bridges

		and molar endodontics if you're having them under general anaesthetic' (DP4) 'So we did emergency treatment that day which was very basic, and it was not gold standard. but it was the best that we could do for him given the fact, it was a complete new scenario, a new situation, new surroundings' (DP13) 'I think you have to, the clinician, you have to lower your expectations about what you can achieve in each visit, you have to accept that some days you're going to be making loads of progress, the next week you might have been back three or four steps because it's not a good day, they've got another stress in their life going on or something's different' (DP16). 'I think that most orthodontists when they see a patient with autism will tend to reduce, the, outcome measure, they will tend to reduce the anticipated outcome of the treatment in other words, instead of maybe aiming for perfection, they'll tend to reduce that slightly to right we're going to achieve the best we can here maybe eighty percent, but we're not going to get one hundred percent cos, t's just going to be too difficult, I think that's probably most people's attitude actually' (DP6) 'Because I know the waiting time of the funding for community hospitals is really long and you know I know people that work in community that will say that basically a lot of their patients that they see for like inhalation sedation and patients that have to go to hospital for general anaesthetic is not necessary and they could have had it done in general practice. But I think there is an attitude of "oh we're not even gonna bother trying". I think that sort of attitude needs to be wiped out among general dentistry' (DP14).
	b) Reduce uncertainty	'its all about explaining you know in detail what's going to happen, what they're going to

		feel, what they're going to see you know and just preparing them basically and usually they're fine with that' (DP14) 'he always sees the same therapist; he always sees the same nurse, and he always sees the same orthodontist. He comes at the same time on the same day, and although it's you know eight weeks in between. We do not keep him waiting, if we know that he's in. You know, if his appointment is at half past two, he goes in at half past two. And it's very - everything runs to clockwork where he's concerned' (DP2). "They go in and they desensitize themselves to the surgery and they get a shot in the chair, put the glasses on, put the bibs on, have their teeth brushed. Familiarize themselves with the mirror and we give them, a consistent, a routine when they came into the surgery, so they know what to expect (DP7)" 'And quite often we just tend to find that giving them double the length of the appointment than you would, and you, certainly in the early stages until were used to what's happening and they've got the appliances on' (DP2) 'From what I, we do is, I just extend a little bit more time for autistic patients, a little bit more time for treatment. And I put braces in stages. I don't put all in one go, so that they get used little by little' (DP5) "For a significant proportion of my children who have an autism diagnosis, it may take them a, a little bit longer, or significantly longer to attain, what I call are the dental life skills like, being able to enter the surgery, being able to sit in a chair, allow a dental exam, accept a toothbrush, accept fluoride varnish, accept air water suction and be able to understand why they're there and what's involved, put glasses on, put a bib on, and make that a normal part of their dental experience (DP7)."

	c) Consider the sensory environment	‘They they like a sort of calm environment. If they’re in a calmer environment, they make themselves calmer’ (DP1) ‘Some of our autistic patients wear their headphones the whole time or you know ear defenders if they want to do that and things that’s fine’ (DP16) ‘face mask, a plastic mirror, a tube of toothpaste…a toothbrush in there and there will be a little sort of card and it show you the dentist and the chair but it’s all just reinforcing all this; (DP12) ‘We're particularly careful from the desensitizing and acclimatizing to fluoride varnish. It’s got a strong colour, taste, texture, smell, so we’re quite careful there’ (DP7). ‘In some of the surgeries… we can use you know the dimmer switches to keep things a bit more tranquil and not as bright and harsh for them’ (DP16). ‘to be able to provide a clinic, so for example on a Wednesday afternoon, that clinic is specifically to see patients with additional needs. But getting that support and that funding... never going to happen in a month of Sundays. Certainly not in the economic climate we've got at the moment, but that's something we were looking at and wanted to do’ (DP2).
	d) Ensure effective communication	‘I, explain things very clearly and I always ask their permission before I look in their mouth, I say ‘please can I look in your mouth’, and ‘I have to, look at your teeth carefully’, ‘we might have to touch your lips to move them out of the way, so I can see what I'm doing’ (DP10) ‘you need to be quite straightforward in the way you explain things rather than using allusion or jargon or nicknames for things, just be straight down the line and say exactly what you mean.

		Because, I'll give a silly example, but if you say 'Can you hop on to the chair?', somebody very literal-minded type of autism and might literally mean you're going to hop onto the chair as supposed to get onto the chair' (DP4) 'And I always make sure I'm, very, very careful to explain what I'm doing before I do something, and give them lots of explanation, lots of encouragement and reassurance' (DP10).
	e) Focus on prevention	'so I would say that early intervention is key to avoid any traumatic situation, and start a gentle introduction to dentistry' (DP15) 'I think with autistic children, dentists should really concentrate on prevention because for a lot of them they struggle to accept treatment. If you reach them early with good prevention messages, then hopefully it will mean that in the future, they won't need to have extensive dental treatment done' (DP3) 'where we do we provide prevention and tooth brushing programs and fluoride varnish programs for our ASN schools, that's an additional support needs schools. There's a high ratio of children who have autism who attained these skills' (DP7).
	f) Importance of disclosure	'Yeah, so I could create more time for patients, but only if I know in advance. So, it's a question of, if you've got the information then it's easy to adapt the next appointment cos these patients are often under treatment for eighteen months to two years, maybe even longer than that' (DP6) 'It's information that the parents may feel that it, just didn't occur to them that it would be information that would be useful to us in terms of helping manage their child, and sometimes you have to tread quite sensitively and carefully to identify if there is a diagnosis there or not' (DP7)
3. Crucial role of the caregiver	*a) Valuable source of guidance*	'parents are skilled in supporting their children whether they have autism or not within the dental surgery' (DP7)

		‘so I believe in in finding out as much as I can about the child … learning about them and learning from the parents because the parents are the experts, asking the right questions and listening carefully to the answers is important’ (DP11) ‘you just have to listen carefully to what parents say to you. I think we are getting quite a lot of clues from parents as to what the best way is to go about treating patients with autism’ (DP9).
	b) Use of incentives	‘But then a family friend had said “if you were able to wear your twin block, I will buy you a computer game”. So he decided he was going to wear his twin block and actually he's been wearing it really effectively, since then’ (DP9) ‘There was another one that used to well he still come and see us, and he's got to have a huge gift… he doesn't get it, until he's allowed us to have a look in his mouth’ (DP12).
	c) Need for caregiver to model good practices	‘The parents that we tend to see, when they realize that we’re going to do the best for the child and they see that we've got the time and everything else, it is very sort of patient centred, then they work with us, but the diet and the toothbrush a home can still be a problem’ (DP12) ‘We found particularly that his mum was very lenient with him, and just let him. there was no, there was no kind of, oh what's the word... I don’t want to say strict. because that's not correct. There was no interaction from her to help control the situation, and we in the end had to sort of ask her not come in to the surgery. And he dealt with it much, much better when he didn't have his mum there watching’ (DP2) ‘I think it's like any parent or carer they can vary, and you have someone very supportive, and will really sort of push you to get the best for their child or person that they’re caring for but, others who aren't so helpful and might not persevere

		with the brushing, persevere with bringing them to the dental surgery so, lots of variation. Well, that's not the right word but other people that support and people who don't necessarily give as much support, and some are excellent' (DP8).
	d) Impact of caregiver's anxiety	'I think sometimes the parents can be an issue. They tend to almost pre-empt how the patient is going to react and they'll tell us 'he's not, oh this patient's not going to have the treatment, there is no point in you even trying, you should refer him straight away' or her should I say. And I think that sort of negative talk in front of the patient, that can sometimes make it so that they have this idea, it's almost like a self-fulfilling prophecy' (DP14) 'mum herself was quite anxious about dental treatment, and we know that that will offsets, if you've got an anxious parent, it makes the child anxious' (DP13).
4. Importance of specialist knowledge	*a) Desire for further training*	'I think it would be good if there was more training for general dental practitioners if there was more, sort of local courses and things they could go on to with tips for treating patients with autism. I think if the local deaneries put on the courses, I think it would be quite good' (DP8)
	b) Mixed knowledge regarding where to seek guidance	'I would be able to access stuff in the autism society and also BSDH website' (DP4) 'No, I don't know any like official sort of resources that we can use, I don't know of any' (DP14)
	c) Reliance on personal and colleagues' experience	'I've gone through specialist training, I know a lot of consultants in paediatric dentistry both, professionally and, on a personal basis. I'm very lucky to be located within a site where, you know, where we work as a team. So I work in a team of paediatric dentists. We're allowed to have peer group meetings periodically, so, we have peer review, we have direct access both professionally and personally to colleagues who

		are, qualified specialist and consultant levels' (DP7) An awful lot of it, I've learnt by doing. You know, just by having encountered lots of patients in the autistic spectrum, you get the experience of "well this worked before, we'll try this… we know this doesn't work". That sort of, that sort of thing. And you start to recognize patterns in the patients, things you've encountered before (DP4). 'if I have a particular problem with a patient, I have colleagues, who are also in special care dentistry, other specialists, and can talk to them about the patient' (DP4)
	d) Different levels of experience, resources and expertise	'I think because general dentists don't necessarily have the a) the training b) the experience and that parents can feel a little bit frustrated. So therefore they want them to be referred to a paediatric dentist, or you know if it's an adult if they're a little bit older then being referred to special care. because they know that we've got the time and experience to be able to deal with that' (DP3) There's a huge difference and so the children that the staff that you see in a high street dentists surgery will be less familiar with autistic children because that's not who they see most autistic children go to the salaried community dental services so, if you ask a nurse from the community dental services, then they will know something a lot more about autism then a nurse from the high street (DP11). 'I think, because I'm in special care they [dental nurses] have a lot of experience in, working with patients with autism, but the training, we do receive, some training so I think because of where I'm working, they are trained but maybe in general practice, they might not be (DP8).' 'the kind that we get in community, I think is we can give them as much time as they need within, you know within some sort of barrier but we're not looking at the clock all the time because

		they're the parents who children who were seen or the other carers of the adults that were seen, understand that when it gets to their turn, their child or their adult is in the chair, they will get as much time as they need and they know that. So, it's not like being in practice where you know you've got a patient over 20 minutes and you've got to stick to it. And that's why we end up, with all the referrals because, they don't get the kind of practice we do a lot of them, you know, family and friends, and you know questionnaires and feedback we get is 'you've got so much time', 'you've got time to listen to them' you've got time to sort of like do things the way they want them to do. So, I really do think we're getting it right, whether we had any more time I'm not sure because I do think they have a certain time span and once that's over, you've got to withdraw treatment, you can't keep go, you know what I mean' (DP12) 'A lot of the children who come for repeated appointments, but not sent back, they're referred in to us and they're not sent back to their own dentist because they wouldn't get the treatment that we can provide for them the kind that they need and everything else (DP12).' 'and the other remit is to provide regular routine dental care for children where there are too many barriers for them accessing sort of primary care type service with the normal high street dentist.' (DP7)
	e) Tendency to refer on	'You have dentists who are trained in everything else, but as soon as somebody with some special needs is, 'oh you've got to send them to somewhere else'. 'You've got to send them to community' because you don't know how to deal with them, you've never been taught, you've never been exposed to' (DP12) 'Sometimes people see the diagnosis [autism] and think, or just read it on the medical history

		form, and just think "Oh that's going to be a bit difficult. Let's move it on"' (DP4).
	f) Integration of services	'I mean there's another young man that I've treated a few times over the years, and he actually goes to an ordinary dentist for his checkups, but when he needs treatment and they can't manage to get it done, they send him to see us for a short course.' (DP4) 'We liaise and work closely with our colleagues who work in tertiary care, our consultants in paediatric dentistry, so, we'll get a very good strong network and we've got a good working relationship with our general dental practitioner colleagues as well. So, actually for some children we'll do a shared care agreement where, they'll remain registered with their own general dental practitioner but we might provide certain aspects of a child's dental care, maybe the fissure sealants or, desensitize them to fluoride varnish, and then just maybe seeing them yearly, but the dentist who they regularly, who they're registered with, they would see on a more regular basis' (DP7).