

Open wide?

*Families' experiences of
accessing dental care
for their disabled child*

Jill Harrison

Contact a Family

Final report: September 2005

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'My experience is that I have had to change dentists because it was not possible for a wheelchair user to access the surgery. I have now found another NHS Dentist locally in South London whose premises are completely accessible. He is sensitive to the needs of my daughter, who is profoundly mentally and physically disabled.'

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Foreword

With so much media interest in access to dentistry of late, it is easy to forget that, for many, accessing dental services has always been a problem. The British Dental Association has long argued that quality dental care is imperative across the UK, regardless of geography, or age, or physical or mental ability.

There is little doubt as to the high value that the families of disabled children place on the services dentists provide, whether on the high street or in specialist clinics. However, what this report also highlights is the obstacles placed in families' way in order to obtain the most suitable care for their child. What is clear is that there must be a unified system of collating and providing information to families, and the British Dental Association is pleased to read the recommendations within this report.

It is impossible to suggest solutions without properly understanding the problems facing special care dentistry. The Salaried Primary Dental Care Service (SPDCS), which, as this report shows, provides most special care dentistry at a primary care level, has evolved in an essentially piecemeal fashion. It is widely regarded as a Cinderella service - both within Primary Care Trusts and within NHS dentistry as a whole - and a patchwork service, without overall national coherence.

Underlying these characteristics has been the lack of a broad, long-term strategic vision at a national level for the service, which is why some areas benefit from better provision than others. The service consistently struggles with shortages of funding and workforce, with a number of Strategic Health Authorities reporting three month vacancy rates for dentists of almost 20 per cent.

There is no 'quick fix' for special care dentistry, but, as this report shows, when it works well, the benefits that are felt by disabled children and their families are great. The fundamental problems outlined in this report must be addressed if we are to ensure that these benefits are felt by *all* disabled children.

Janet Clarke
Chair of the British Dental Association's
Central Committee for Community and Public Health Dentistry

Chapter 1 Introduction and methodology

1.1 Introduction

There are over 700,000 disabled children in the UK, the majority of whom live at home with their families. Each day, seventy-five children are born or diagnosed with a disability. Contact a Family provides support, advice and information to families with disabled children across the UK. Each year our helpline and local information services support over 18,000 families, and a further million parents and professionals visit the website www.cafamily.org.uk. Contact a Family uses the experience of these parents to lobby Government to try to bring about positive change for families.

This report describes the findings of a two-month consultation exercise on the theme of access to dentistry in families where there are one or more disabled children. The work was carried out by Contact a Family who also analysed the data and produced this report.

Contact a Family hears from many parents about the difficulties they face in obtaining healthcare, as well in many other aspects of daily life – such as trying to get a break, lack of information and financial problems. Previous research (Contact a Family, *No Time for Us* 2004) has indicated that 76 per cent of parents experience stress or depression. There is a wealth of evidence that families with disabled children are more likely to experience poverty (e.g. Department of Social Security, *Households Below Average Incomes* 2001).

Parents with a disabled child already lead complicated lives and where they are trying to juggle paid employment with arranging a myriad of assessments, appointments and reviews for their child, this complexity increases.

1.2 Methodology

This survey incorporated two components:

- A web-based survey
- A request for parents to contact us with their own qualitative stories about accessing dental care. As part of this process, we also spoke to both national and local support groups, a Community Dentist, the British Society for Disability and Oral Health and the British Dental Association.

The survey

The Internet survey was essentially a short questionnaire asking key questions of families. It was posted on the Contact a Family website from mid April 2005 to the end of July 2005. This survey received 808 responses from parents in the UK and a further 66 from outside the UK, which have been excluded from the analysis, although their responses are reported at appendix c. In addition a further 22 parents sent emails or letters with additional stories or comments. A copy of the survey questions appears at appendix a.

Quotes from the parents who emailed or wrote to us with additional comments are reported verbatim in italics. The only details changed are those which could identify the particular child or family or a particular dental practice.

1.3 The report

In summary therefore, this report brings together the views and experiences of 830 UK parents with a child with a disability.

Part 2 describes the key features of the families who responded to the surveys. Part 3 describes the parents' responses to the various questions posed.

Part 4 outlines how some parents groups have worked to improve dental services in their area or for their clients. Part 5 presents the policy implications, recommendations and conclusions.

1.4 Dentistry in the UK

There is a widely-recognised shortage of dentists in the UK. Closures of dental schools in the late 1980s and early 1990s has significantly restricted the number of new dentists coming into the profession, leading to a situation today where the Department of Health estimates that there is a 1,850 shortfall of dentists in England alone. Although the Government has begun to address these issues, with an increase in undergraduate places from October 2005, it will take five years those dentists are fully qualified. In addition, dentists working within the NHS were hit by a cut in fees in 1992, leading many of them to reduce their commitment to the NHS. Because of a lack of commitment to dentistry by successive governments, many patients struggle to access dental care, whether as private or NHS patients.

We know that there are increased risk factors for having tooth decay (dental caries) related to socioeconomic status, medication, diet, the presence of chronic disease and other factors. Rampant caries is a disease of deprivation which is more common in inner city areas, in children from minority ethnic backgrounds and amongst poor families. Children taking long term medication can be at greater risk of decay because of the sugary solutions often used to make such medication more palatable.

The consequences for disabled children of inadequate dental care can be very serious. For all children, dental decay can cause pain, problems in chewing and eating, speaking and also self-consciousness. For children with certain health issues or disabilities the consequences can be more serious. Those with compromised immune systems can be at risk of developing complications which in some cases can be fatal.

The Community Dental Service (also called the PCT Special Care Dental Service) provides treatment for people who may not otherwise seek or receive dental care, such as people with learning disabilities, elderly housebound people, people with mental or physical health problems or other disabling conditions which prevent them from visiting a family dentist. One senior dentist, working for a Community Dental Service in the South East told us:

'Early contact is key for disabled children and pre term babies. Ideally we should see children as soon as their first teeth appear, not at two or three years old. Families need to be able to self refer to us, in order to minimise the barriers which stop families accessing early preventative care. I try to visit all newly diagnosed families at home, to offer advice and support on subjects like brushing and fluoride use. In part, this is to reassure parents and build their confidence – for example, I tell them not to worry if their child cannot spit yet. When we ask what parents with disabled children value about community dentistry they tell that that they aren't made to feel that there is time pressure, they value our empathy and patience and the information that we can give them, for example on how diet can affect teeth. There are other techniques that we can use to build confidence in the child too – such as allowing social visits - to help the child get used to new environments, without any hands- on treatment and having our photograph taken to show the child. Of course resources can hamper our ability to visit everyone at home who could benefit from this service.'

The British Society for Disability and Oral Health told us that
'All too often we hear about problems such as inaccessible premises, dentists being unwilling to come out to their home, extractions of teeth being offered instead of conservative treatment to repair them and dentists not being confident about providing treatment because of their lack of knowledge of the condition and referring them to a dental hospital in a regional centre many miles away.'

Contact a Family wanted to see whether families with disabled children were having particular problems with accessing dental care and treatment and what their experience had been. We felt that it was possible that families with disabled children may face additional barriers to accessing care for a variety of reasons.

1.5 Challenges facing families with disabled children.

There are a number of clear challenges which face many families with disabled children in their day to day lives.

- 1) Physical barriers. Despite the Disability Discrimination Act, some premises remain physically inaccessible. If the dental surgery is accessible, public transport to get a family there may not be.
- 2) Attitudinal barriers. There is some evidence that dental care may be perceived as a low priority (e.g. Lowry et al 1996 *Under-registration of dental care for children with heart defects in the north east of England*). This may be both from parents who already spend a large amount of time attending various medical appointments or from dentists who may find disabled patients more challenging and discourage attendance either overtly or covertly.
- 3) Financial barriers. We know that around 55 per cent of disabled children grow up in or around the margins of poverty (Gordon and Parker 2000). Although dental healthcare for children under 19 is free in the UK, taking time off work to accompany your child to an appointment may have cost implications in lost wages and travel expenses. Parents may also feel under pressure to have their own teeth checked (which, for many, is not free).

One mother's story illustrates the amount of time spent caring for her disabled child.

'In her first five years, we have had contact 774 times with health, education and social services professionals. I have spent 4,942 hours on appointments and telephone calls relating to my child's needs and driven over 11,000 miles. In contrast my (non disabled) son had 29 appointments in the same time period'

In Contact a Family's previous research into employment (*Flexible Enough?* 2004), 30 per cent of parents said that taking time off work for a myriad of health, school and social care appointments was a major problem. There was also a strong feeling from the parents we surveyed for that report that there should be paid leave to take children to essential appointments.

'A crisis can arise at little or no notice which can result in not turning up at work or leaving without warning. Hospital and therapy appointments are also always within working hours.'

'So many hospital appointments and operations and some illness to cover. Sometimes the problem is sheer exhaustion and stress'

'If the consultant has his clinic Monday am, that's when you go, not Thursday pm coz it suits your boss'.

'Although I am always given the time off to attend appointments, I feel that I don't like to let my employer down'

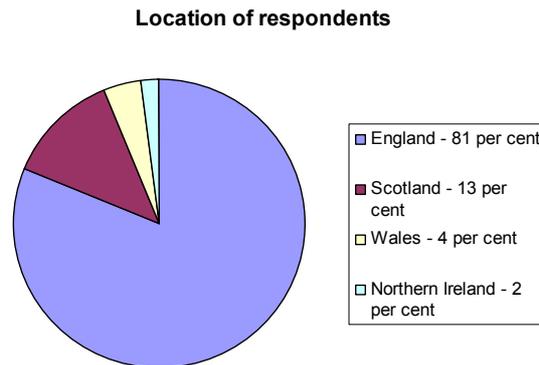
The remainder of this report looks at parents' experience of dentistry and how any barriers may be overcome.

Chapter 2 The respondents

Respondents were asked a number of questions about their location and family situation as well as their experiences of NHS dentistry. The full questionnaire is attached as appendix a.

2.1 Location

Respondents were asked to indicate where they live.



An additional 66 parents indicated that they live outside England, Scotland, Wales and Northern Ireland and they have been excluded from the main body of the results.

2.2 Disability

Parents were asked whether their child has physical disability, learning disability or behavioural difficulties. Parents could indicate more than one kind of disability.

Of the 808 parents in the main survey:

51 per cent had children with physical disability

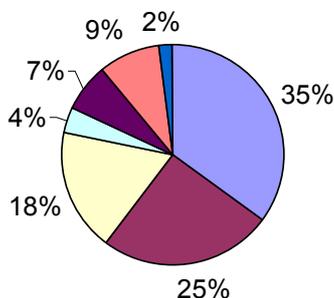
67 per cent with learning disability

42 per cent with behavioural problems.

Fourteen per cent said that their child had physical and learning disability as well as behaviour problems. The vast majority of children (94 per cent) had more than one kind of difficulty or disability.

Chapter 3 Parents experiences of dental services for their child

3.1 Parental satisfaction with NHS dentistry



- Very satisfied with the NHS dental care their child had received
- Quite satisfied
- Some problems with some aspects of the NHS dental care their child had received
- Quite dissatisfied
- Very dissatisfied with the dental care their child had received
- Did not use NHS dental care for their child
- Did not answer this question

In view of the small sample sizes from Wales and Northern Ireland, we have not attempted to draw conclusions about levels of satisfaction in these nations. However, Scottish respondents were somewhat more likely to say they were very dissatisfied with services. Eleven per cent of Scottish respondents were very dissatisfied compared with five per cent of English respondents. They were also somewhat less likely to be very satisfied than their English counterparts (25 per cent compared to 37 per cent). Overall the proportion of Scottish respondents who said they were very or fairly satisfied was higher at 67 per cent than the English families at 59 per cent.

We do not know why nine per cent of parents had not used NHS dental services. It may simply be that their child is at yet too young to need to go to the dentist.

Some of those parents, who emailed or wrote in with their stories, told us how helpful a particular practice or individual had been to them:

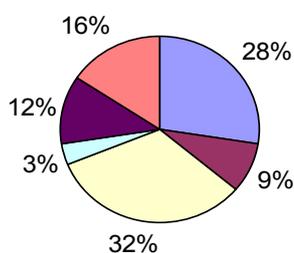
‘My son has severe learning difficulties and presents with quite challenging behaviour at times, particularly in unfamiliar surroundings. I take him to see a dentist in Cheshire. She is marvellous, wonderfully patient and goes out of her way to try and make both of us more relaxed. She arranges for us to go every 3 months for a check up - this has been the case since he started going at the age of 6 and he's now 13. When we first went he wouldn't even open his mouth, he will now, but so far we've never got him to sit in the seat. This doesn't deter her and most examinations are done standing up! If she can't see all his teeth she doesn't get cross, she just makes a note and next time she will concentrate on the ones she missed the previous time. She's a wonderful lady, always calm and smiling. I feel very lucky that my son has her for his dentist as we couldn't ask for anyone nicer!’

Several parents mentioned how hard it was to find someone who understood their child's needs.

'We had a hard job to find our dentist and went to see several before we found this one, who was recommended by another family. But he is really good with my daughter and I've also recommended him to other parents whose children have special needs. Once you find a good one, its OK, but it's the looking that is hard. I would advise anyone to ask other parents.'

3.2 Particular problems with aspects of dental care

We asked whether parents had experienced particular problems with aspects of access to dentistry – whether these were physical, financial or attitudinal barriers. Forty-nine per cent of the parents questioned had not experienced any of the problems we set out. However, significant numbers of parents had experienced a variety of problems.



- Unable to find a dentist to take their child as a regular NHS patient
- Unable to find an NHS dentist to treat their child in an emergency
- Problems finding an NHS dentist who is sympathetic to the needs of disabled children
- Had to pay privately to get their child the care they need
- Had to let their child go without treatment because they were unable to find an NHS dentist and could not afford to pay
- Had problems getting physical access to a surgery

Results across the nations are consistent in most respects. The only significant difference is that Scottish parents were much more likely to struggle to find a dentist sympathetic to the needs of disabled children. Thirty-nine per cent of Scottish parents had found this to be a problem compared to 17 per cent of English parents, 11 per cent of the Northern Irish sample and nine per cent of the Welsh sample.

Some parents were clearly worried about getting help for their children and were not finding it easy to find someone who was sympathetic.

'My daughter has a rare disorder with many problems one of which is severe peg teeth. She has seen the school dentist who is very unsympathetic to her needs and has also seen a specialist who was not able to tell me much. I wonder what can be done for her teeth and whether she will have peg teeth for the rest of her life or

whether there is a treatment available to make her look like everyone else when she smiles.'

'I live in the North West, my daughter has not seen a dentist for approx. 16 months, as the SEN dentist has left and they have not been able to appoint a new one, on inquiring the other day it may be some time before one is available. They asked if she would be able to see an ordinary dentist, but she needs to see someone who can work with her, and has experience with special needs children. I think regular check ups are important, as some children cannot tell you if there is something wrong.'

Particular disorders brought about their own particular issues:

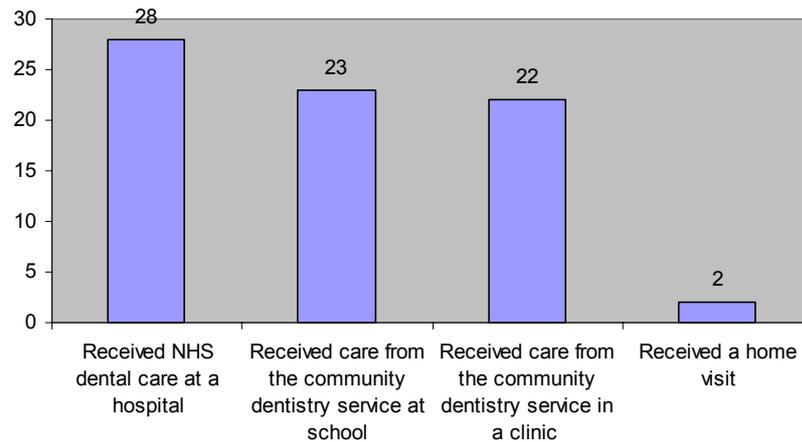
'The ITP Support Association support adults and children with the rare autoimmune bleeding disorder Idiopathic Thrombocytopenic Purpura. This is a rare bleeding disorder that can cause severe bleeding from tooth extractions so it is sometimes important that adults and children should be able to find a dentist with some expertise in ITP. At one time they could get referred to the Dental School but they no longer accept referrals. One of our members wrote to say that he was seeing an excellent Professor at a Dental Hospital in London. I contacted the Prof. to see if he would accept referrals, but received a lengthy sympathetic reply explaining that it was not possible as they have no A&E, ITU or haematology dept on the same site. He states that it is his strongly felt opinion that all haematology patients should be treated within their own unit with dental services bought in and provided on site. The situation for ITP patients is dismal. My own ITP son has never had any treatment on his teeth, not even cleaned, by two different dentists. It may be that he is fortunate and needed no treatment, but I have often wondered if they are just scared to touch him!'

'My experience is that I have had to change dentists because it was not possible for a wheelchair user to access the surgery. I have now found another NHS Dentist locally in South London whose premises are completely accessible. He is sensitive to the needs of my daughter, who is profoundly mentally and physically disabled.'

It is especially worrying that seven per cent of parents had had to let their child go without treatment because they could not find the care they needed on the NHS and could not afford to pay.

3.3 Services received

We also asked whether parents had had occasion to use particular services for their child, namely dental care at an NHS hospital, care from a community dentist on a mobile unit at school, a home visit, care from the community dental service at a clinic or none of these. Thirty-eight per cent of parents said that their child had received none of these services.



Children in Scotland and Northern Ireland are much more likely to have received care from a mobile unit at school than parents in England and Wales. Almost half of parents in these countries had received that service compared to under a quarter in England and Wales. Parents in Scotland were also more likely to have experienced hospital care (46 per cent) than English parents (25 per cent).

It is particularly worrying that only 2 per cent had received a home visit from a dentist, given the importance placed on this type of service by the Community Dentist we interviewed.

Parents have mixed experiences of many of these services. For example, two parents emailed with contrasting experiences of hospital care:

'My daughter also has treatment at a dental hospital. She has recently moved from the children's Department to Adults Special Care Unit. I have found this excellent. There is a surgery specifically for wheelchair users which allows the patient to stay in the chair, but the chair can be tilted in a similar way to a dental chair. The specialist who treats my daughter is extremely sensitive to her needs but also determined to give her the equivalent access to treatment that anyone else with less complex needs would have.'

'We were referred to the hospital dental dept last year due to concerns our family dentist had with possible bleeding issues when my daughter's teeth were due to fall out in readiness for her adult teeth. We have never seen the Consultant (who is reported by other families to be very good with children with disabilities!). We have seen the same Doctor/Dentist. She asked me the usual question to begin with on the first appointment: - Tell me her history!!!! I suggested she look in her hospital notes, they were on the table. She said "I am feeling lazy". We therefore got off to a bad start and I remember her words very clearly - I have repeated them to many people, both parents and professionals to demonstrate that families are never allowed to feel "lazy"!!!! (My daughter is seven years old and therefore did not have a short history and the notes were very comprehensive).

On a subsequent appointment this Doctor/Dentist thought she would be able to paint her teeth with fluoride stuff used to protect teeth in out-patients. I pointed out

then and since that this is totally impractical for a child who does not have the understanding of any explanations about being still, not licking etc. etc. She also does not comprehend that my daughter has frequent general anaesthetics so why cannot this procedure be done combined with another?? She says the fluoride is not essential enough to have a GA or other medical personnel do not like dentistry being done with their lists!! Yet again we are left feeling that hospital protocol takes precedence over a child's needs or best interest!!'

For some parents the Community Dental Service, at school or at a clinic has been a lifeline:

'My son would not cooperate with any dentist. I always ensured that he saw the school dentist on a monthly basis to get him used to everything. He also saw a NHS dentist every six months on the basis that if anything was required doing he would not be asked to do the work. We then noticed that he had two rotten teeth at the back. They (school dentist) referred me to the Dental Hospital.. They were wonderful and monitored our son very closely. They checked frequently to ensure that the rotting teeth were not causing any pain. This was hard work and meant that we visited every month at a set time on a set day (this is partly due to his Autism and that of his brother's Autism.)

When it was time he went into the hospital part and had a general anaesthetic. They removed two teeth, filled two and gave his mouth a thorough check. We then went back for several visits so that my son would not feel that they only wanted to operate. We have now been discharged and he sees his own NHS dentist every six months. He cooperates more now, but it is always a very quick look before the mouth closes and he is off. However, the dentist has got quicker and quicker at looking at his teeth and is more than happy that he gets a good enough look at them. The dental hospital have also told me that I can go back at any time and do not need to be referred, so I know if there is a problem I will have no trouble in getting him back there.

I would say that without the work of the school dentist and the regular visits to the dental hospital, I don't think I would have ever have got him to open his mouth, but it gets better year on year and we no longer have to do 20 mile round trips on a regular basis as his NHS dentist is within walking distance of home.'

'We have a very positive experience of dentists under NHS as we are in London and have access to the very wonderful Specialist Paediatric Dentist at the health centre. I believe another parent told me we could get referred and we were referred by community paediatrician, the dentist or her colleagues who are also lovely, see all of our children - autism and SLD, doesn't want to sit in chair etc etc, behaviour issues, coeliac disease and mild motor delay.

All SN children should have access to the specialist community dentist service. Our experience has been very positive; there has been no issue with her seeing all our children.'

'The Community Dentistry Service is wonderful, but no-one knows about it. Trying to get information is like wading through treacle'

Chapter 4 Parents working to improve dental services

4.1 Introduction

A great deal of recent legislation and guidance on health, education, social care and the early years mentions the need for user participation. This is leading to some imaginative and cost-effective developments in local services, based on what works for families.

Increasingly a range of professionals are involving parents in influencing services. However, it is often a challenge to turn good intentions into effective practice, and to find ways of working with parents which makes best use of their knowledge and insight while supporting them in the process. Successful partnership with parents all too often depends on the drive and commitment of individual workers, rather than being embedded in the culture of the organisation.

Parents can and do become involved in influencing dental services at local and national level and the results can be hugely beneficial for families.

***Case study 1:
Influencing at a national level – the example of the Ectodermal
Dysplasia Society***

Ectodermal Dysplasia (ED) is not a single disorder, but a group of closely related conditions. More than 150 different syndromes have been identified. The Ectodermal Dysplasias are heritable conditions in which there are abnormalities of two or more ectodermal structures such as the hair, teeth, nails, sweat glands, cranial-facial structure, digits and other parts of the body.

Before a developing fetus is large enough to be seen, a layer of cells covers the outside of the body. This surface layer of cells is called the ectoderm, and from it develop the skin, hair, nails, teeth, nerve cells, sweat glands, parts of the eye and ear, and parts of some other organs. Each of the listed parts of the body, then, is called an ectodermal structure. There are many disorders that involve one of these structures only and are not properly called ED. Any combination of defects involving more than one of these structures, however, should be called an Ectodermal Dysplasia syndrome; the list of such combinations is extensive. For example, one person may have missing teeth and defective nails, while another may have missing teeth, inability to sweat and sparse hair. Still another may have sparse hair and a hearing loss. Each combination of features represents another type of ED syndrome and has a specific name.

The severity of the condition varies from individual to individual and family to family. Many individuals have only a very few teeth and some will have milk teeth only. Others have very pointed eye teeth.

The ED Society says that the main problem they have is persuading dentists to work on children's teeth sooner rather than later. Many dentists will look at a child with ED and tell the parents that the child should come back for dentures or other work at the age of 12 or 13. In fact, work to square off the eye teeth or to fit dentures can begin when they child is as young as three years old. The Society feels that starting

school before any work is carried out exposes the child to teasing, name calling and bullying. Many of their children are bullied for their appearance. For example, being called a 'vampire' because of their teeth is not uncommon. Unfortunately, it is not uncommon for these children to need psychiatric care in older childhood as a result of their early experiences of bullying. If dental work starts at three years old, in the Society's experience, this leads to a much happier school life and fewer problems in older childhood.

The Society believes that dentists have little experience of working with disabled children. Their view is that dentists 'tend to treat the teeth and not the child'. They also believe there is limited understanding of the effects of a facial difference on children's psychological wellbeing and therefore little understanding of the need for prompt treatment. In their view this limits their ability to give good advice to parents. Dentists are really crucial for children with ED as it is they who might make a referral for diagnosis. Problems with teeth often give a first clue that the child has ED. Children with ED might also need to preserve baby teeth for as long as possible and there is a need for use of fissure sealants to try and preserve them, yet many dentists do not seem to understand why this might be necessary. As children get older, they may want implants, which can cost up to £30,000, a significant amount of money which could deter NHS intervention.

The ED Society has specialist medical advisers. They have an international conference each year designed to educate and inform the dental profession all over the world about ED. In conjunction with their advisers, the society has developed a network of 20 dentists, based in hospitals across the UK and Eire, who are interested in, and have experience of working with children who have ED. The Society say that the network has vastly improved the dental advice, care and treatment offered to children with ED and the network members really do everything they can to help the child. In particular their deep understanding of the psychological impact on children is extremely helpful. The Society is able to refer parents to a dentist who will explore all the treatment options with them. Families find this to be an invaluable service.

Although the network has had a hugely beneficial impact on parents and families, they believe there is still a need for better training to help dentists to better treat disabled children and a need for an improved knowledge of disability generally in the dental profession.

***Case study 2:
Influencing at a local level – an example from Yorkshire***

Parents attending a local Children's Centre got together to discuss access to dentistry in the local area with a very good local consultant and the local learning disability nurses and a representative from the local Community Dentistry Service. They decided that dental services for children with autism were in need of some improvement. Primarily the problem was that children with autism were finding the experience of

going for a check up and examination very frightening and bewildering. It was decided to take photographs of the waiting room, the treatment area, the chair and some of the equipment that might be used. This was later turned into a booklet which parents are encouraged to look at with their children to familiarise themselves with the venue and talk about what will happen when they visit the dentist. Furthermore, parents were able to explain some of the features of autism in more detail and this convinced the dentistry service to allow families access to the surgery to look around before any appointment for treatment or examination were made. This greatly helped to familiarise the children with the reality of the surgery that they had seen in the pictures and to visit without any anxiety provoking experiences of discomfort or pain during treatment.

So successful was this collaboration that the parents have also now had an input into the shaping of local accident and emergency facilities in the hospital. The PCT now also holds autism awareness days for staff which parents are involved in delivering.

4.2 How other parents can become involved

Parents wishing to follow the example of these parents, or professionals wanting to improve their own service through parental involvement may be interested to know that Contact a Family produces two guides on parent participation. One is for parents and the other for professionals. Both guides take a practical approach, built on positive examples.

The parents guide is intended for:

- individual parents, who want to find out about how they can play their part in influencing services
- parent groups, who are frequently called upon for a collective parent view
- and parents who take on the role of parent representative on working parties and strategy groups.

The professionals guide aims to:

- raise awareness of the opportunities for parents to play an active role in shaping services
- encourage parental participation, by giving examples of parent initiatives and successful joint working between parents and professionals
- encourage parent representatives and parent groups to be proactive in requiring appropriate standards of support and recognition for the contribution they make.

Both guides can be ordered from Contact a Family on 020 7608 8700 or via the Contact a Family website www.cafamily.org.uk

Chapter 5 Policy implications and conclusions

5.1 Information from the NHS and other statutory bodies

Some of the comments made by parents indicate that it is difficult to access information about finding a suitable dentist, particularly information pertaining to the Community Dental Service. This has meant that many parents rely on word of mouth recommendations from other parents. Certainly, the importance of this source of information cannot be overestimated, particularly from those who are members of a local parent support network or a national group for a particular disorder where other members may have very valuable experience to pass on.

However, for all parents, including those who are more isolated, more formal sources of information should enable them to identify dentists with expertise in disability issues more readily.

A search on the NHS Gateway www.nhs.uk/England/Dentists/Default.aspx for example, revealed that while it was possible to search for a dentist providing 'services to patients with special needs' in London only 10 Community Dentistry Services came up as a result. All of these were in South London. Searching for particular Community Dentistry Services in north London which we knew existed brought no results. Searching for 'Community Dental Service' as the name of the practice in a particular area of South London which we knew had a service yielded no results, but searching for 'CDS' did bring up the details.

Where high street dentists were listed under 'services to patients with special needs' there was no indication of what these might be – for example whether the surgery was physically accessible, had experience of children with autistic spectrum disorders or whether communication in British Sign Language were possible. This is the kind of information which parents would find very useful.

The information about services offered through high street dentistry needs to be much more comprehensive and all community dental services need to be accessible via the search facility. Searching for 'Community Dental Service' should also produce concrete results, rather than just the acronym 'CDS', which may mean nothing to patients and their families. As some services require professional referral to access them, it would be useful if these protocols were outlined.

NHS Direct Online simply refers to www.nhs.uk for dental searches and so would yield no better results. It does have a 'Frequently Asked Questions' section. In answer to the FAQ 'How do I find a dentist?' the patient is first given the telephone number of NHS Direct and later on the following description is given:

'The Community Dental Service provides treatment for people who may not otherwise seek or receive dental care, such as people with learning disabilities, elderly housebound people, people with mental or physical health problems or other disabling conditions which prevent them from visiting a family dentist.' There is no information about how to access the service. The description does not indicate that both disabled adults and children may be covered by the service.

www.nhs.uk provides the following additional access information

'A Community Dental Service often manages oral health promotion and oral screening for schools. The CDS may provide treatment for children identified at screening, who do not have a family dentist. Some CDSs only accept patients on referral from GPs or from General Dental Practitioners. Your local CDS will be able to give you information about the exact services it provides.'

However, without a comprehensive list of Community Dental Services covering all areas, this is not, on its own, very useful.

We also thought that the other most likely place that parents would search for information would be on their local PCT website. We chose an area of London where we knew that a service existed and attempted to search the local PCT website. Putting 'Community Dental Services' into the search box yielded no results. The word 'dental' on its own brought up the child health section of the website and a section on looked-after children with a telephone number. We telephoned the looked-after children section and were told that dental services for disabled children were via the children with disabilities team. On telephoning this team we were given the correct information. The officer could see no reason why their details were not available on the website. Some detection work was required and we knew exactly what we were looking for (and already knew that a service existed in the area that we had chosen). It is vital that information is made more accessible to families.

Parents will of course seek information in other ways – for example through Social Services, the network of Children's Centres and similar organisations. It is equally vital that such services are also aware of the range of local dentistry options and able to signpost effectively.

Recommendations

www.nhs.uk should provide a comprehensive listing of all Community Dental Services in the UK with a description of access protocols (e.g. via a GP, from a general dental practitioner). This listing may be better collated through a specialist organisation such as the British Society for Disability and Oral Health and the British Society of Paediatric Dentistry. However, it should be available via the NHS Gateway and NHS Direct Online.

When high street dental services describe themselves as offering 'services to patients with special needs', they should be asked to specify what those services might be. Children should be mentioned specifically where appropriate and an indication of membership of the General Dental Council's specialist list for paediatric dentistry would also be helpful.

Children's Centres and other statutory bodies should ensure that they have appropriate local information on dentistry available for parents.

Government should require all Primary Care Trusts and specialist organisations to supply information about all special care dental services in their area in order that this information can be made publicly available.

5.2 Information from the voluntary sector

The National Autistic Society provides an excellent information sheet on going to the dentist, which has many useful tips for families on ways of improving the experience of going to the dentist for someone with an autistic spectrum disorder. It also flags up accessing information about dentistry. By kind permission of the National Autistic Society, this is reproduced at appendix b.

Recommendation

Department of Health should fund other similar leaflets from smaller organisations that may have much useful information to offer to parents but lack the resources to produce it.

Local health and disability voluntary sector organisations should also check their PCT website to make sure that Community Dental Services are flagged up and if they are not, press the PCT to include this information.

Groups involved in the production of local guides for parents should ensure that information about dentistry in the local area is provided (see below for example of good practice):

'You might like to know that we have produced a Directory of Services for Children who are disabled or who have special educational/additional needs. It is available in hard copy and can be found on the council's website. It is called Starting Point. Contained within it is a list of accessible Dentists in our area.' Professional working with families

Contact a Family will also ensure that its own information on accessing health services contains appropriate references to the Community Dental Service and that all advisers are aware of the range of services that may be offered to families. It also behoves us to ensure that families are getting their full range of benefits and tax credit entitlements so that they are not caused undue financial hardship by having to take unpaid time of work to take children to appointments.

It is also essential that the voluntary sector supports, encourages and empowers parents to make formal complaints when the service provided is inaccessible or unsympathetic to their children's needs. Only then will some dental services take on the challenge to improve. Voluntary organisations should receive funding to support individuals who wish to make a complaint and advocate on their behalf.

5.3 Awareness for dental staff

One of the main problems that families have is accessing a dentist who is sympathetic to the needs of families with disabled children. As noted, this was particularly an issue for families in Scotland.

Many parents told us that they have a very good experience of dentistry when they are seen by a dentist who has a special interest in disability issues. It seems from our findings that it can initially be hard to find someone who is sympathetic and who has an accessible surgery, but once you do find a good dentist, the care given is highly valued by families.

Recommendations

We support the British Dental Association and the British Society for Disability and Oral Health in their call for Special Care Dentistry to be a distinct branch of dentistry with specialist status. We believe this will be in the interests of families with disabled children as it will complement the scarce services provided by specialist paediatric dentists and provide seamless dental care for disabled young people as they make the transition to adulthood.

Many dentists working in the Community Dental Service have acquired considerable expertise and clearly offer a service which is very beneficial to disabled children without any professional recognition by the profession as a whole. Disability Discrimination legislation requires all service providers to make their services accessible to disabled people and a special branch of dentistry dedicated to their needs will provide a lead to the profession as a whole and greatly improve standards of care for disabled people.

The British Dental Association said:

“There are historic issues of under-investment and under-staffing in the Salaried Primary Dental Care Service which inevitably impact on the more vulnerable users of the service. The BDA has lobbied successive governments to improve this situation and there has been some progress, but this has often been slow and lacking the sort of change that users and providers might have wished. Those working within the CDS are highly motivated and committed, but often they find that they are stretched by having to cover for vacancies within the team. Many Strategic Health Authorities are reporting vacancy rates of almost 20 per cent, which undoubtedly impacts on the availability of services for those most in need.”

The British Society for Disability and Oral Health told us that

‘These services have been widely regarded as a Cinderella service within the profession and the NHS. This is a patchwork service without national coherence. We believe that the development of a recognised speciality would facilitate the establishment of a skilled workforce with a proper training pathway. It would also enable a list of specialist practitioners covering the whole country to be made available’

Parental involvement can help to improve dental services as we have seen from the examples quoted. Parental involvement in training of dental staff should also be considered, both formally in the qualification routes for the various professions but also informally through practices working with local support organisations of and for disabled people and their families to improve awareness. This would raise awareness of dentists about how many appointments and assessments parents need to juggle, for example. This in turn might help to increase dentists' sympathy when parents ask for the first, or last appointment of the day, or to be seen on a particular day when they are already taking time off work to take the child to another appointment.

We stress that the whole dental team should have appropriate disability awareness. Training for other professionals involved in family care should therefore also incorporate an understanding of disability issues. For example, there is already a comprehensive Certificate in Special Care Dental Nursing which covers various disabilities and how these might impact on oral health, establishing communication with disabled people, the need for longer appointments, access issues, moving and handling etc. The syllabus can be viewed at www.nebdn.org. Many of these elements should be included as standard in all dental nurse training, including the national examination and NVQ qualifications, to reflect the fact that all practices should be open to disabled patients.

The British Society for Disability and Oral Health say that there are some excellent examples of innovative disability awareness training which should be replicated more widely in dentistry training courses. BSDH teachers' group can provide further information about these courses - see www.bsdh.org.uk.

5.4 Resources

No piece of research would be complete without a call for further Government resources. The very few patients who had received services such as a home visit is worrying. A post being unfilled in the Community Dentistry Service for many months, causing vulnerable children to go without treatment, is not acceptable.

The British Society for Disability and Oral Health expressed concern to us that more and more patients seeking a dentist willing to treat them on the NHS are being treated by the Community Dental Service. This is usually as a result of well publicised problems in some areas accessing an NHS dentist on the high street. Their worry is that if this trend continues, this might mean fewer resources available for both disabled adults and children who need this care, cannot obtain it on the high street and in most cases, cannot afford to pay privately.

5.5 Conclusions

Given the bad press which so often surrounds NHS dentistry, we were surprised and pleased at the levels of satisfaction that were expressed in the survey. From the comments made, it is clear that a sympathetic dentist can make a real difference to families who are struggling.

There is no room for complacency however. Finding information is demonstrably difficult and a significant minority of families had clearly had a bad experience of dentistry.

Better information about services locally, better initial and ongoing training and a higher status and more resources for special care dentistry would all help to improve the situation for families.

Appendix a

Access to Dentistry for your child	 <p>contact a family for families with disabled children</p>
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Contact a Family is trying to find whether families with a disabled child in the UK have problems in finding an NHS dentist to treat their child. Could you take a few moments to answer the following questions?

- 1) **Do you live in** (*tick one*)
England Scotland Wales Northern Ireland

- 2) **Does your child have** (*tick as many as apply*)
Physical disabilities Learning disability Behavioural difficulties

- 3) **Which of the following statements is closest to your own view of NHS dentistry?** (*tick one*)
I am very satisfied with the NHS dental care my child has received
I am quite satisfied with the NHS dental care my child has received
I have had some problems with some aspects of the NHS dental care my child has received
I am quite dissatisfied with the NHS dental care my child has received
I am very dissatisfied with the NHS dental care my child has received
I have not used NHS dental care for my child

- 4) **Have you ever experienced any of the following?** (*tick as many as apply*)
I have been unable to find a dentist to take my child as a regular NHS patient
I have been unable to find an NHS dentist to treat my child in an emergency
I have had problems finding an NHS dentist who is sympathetic to the needs of disabled children
I have had to pay privately to get my child the care I want for her/him
I have had to let my child go without dental treatment as I cannot find an NHS dentist and cannot pay for treatment
I have had problems in getting physical access to a dentist's surgery
None of these

- 5) **Has your child ever received any of the following services?** (*tick as many as apply*)
Dental care at an NHS hospital

Care from a community dentist on a mobile unit at school

A home visit from an NHS dentist

Care from the community dentistry service at a clinic

None of these

Thank you for taking the time to fill in this survey. Please click here to submit your answers. We would really appreciate hearing from you with more detailed information about your own experiences of dentistry. If you would like to make additional comments please email helpline@cafamily.org.uk and we will make sure your comments are fed back anonymously to the Department of Health.

Going to the dentist – mini information sheet



Information sheet

Taking all children and even some adults to the dentist can be a very stressful experience. For those carers who have a child with an autistic spectrum disorder (ASD) these appointments can be even more traumatic. This information sheet aims to give you brief strategies which may assist you and help make the experience better for all involved.

Possible Reasons for disliking the experience

* Lack of understanding

Some do not understand the purpose of going to see a man/lady in a white coat, who looks in their mouth and uses strange equipment, whilst they are expected to lie on a chair with a large light positioned on their face. They may not have understood the importance of having healthy teeth and gums and the consequences of not having regular appointments.

* Sensory

This is probably one of the main areas that could trigger large amounts of anxiety for individuals with an asd. The obvious areas being tactile (touch) and auditory (noise). Mouths are extremely sensitive places and for a person with an asd someone putting cold instruments into their mouth could be very painful. In addition the noise of the drills and cleaning instruments could also be a problem. Sometimes the taste of the mouth wash or the paste used can also have an effect.

It is also important to see whether there are any factors in relation to the dentist that cause distress e.g. - Perfume, moustache, colour clothing.

* Invasion of space

Dentists are one of the few professionals who invade everyone's personal space. Most people find this uncomfortable but are aware of why the dentist has to be so close to examine your teeth. For individuals with an asd they may find this close proximity extremely distressing.

The following strategies are obviously dependent on the person's level of understanding and individual needs and should be adapted accordingly.

Strategies to help

* Preparation

As a result of past negative experiences, understandably, many carers leave telling the individual till the last minute or on the day of the appointment. Even though it may initially cause a behaviour pattern change it is in most situations best to try and inform the individual as early as possible. This can be difficult if their concept of time is poor. Using visual

supports, for example a calendar, can help to clarify when an event is occurring. For further information please see the autism helpline information sheet on visual support.

If it is their first visit to the dentist you may like to just go and take them to meet the dentist and other staff first prior to any treatment. You may also like to show them the equipment which the dentist will use and how it works.

It is also important to prepare the dentist and their team, with as much information as possible, so they can make adaptations to the procedure and be aware of the individuals needs.

Try to ensure that the appointment is the first of the day, maybe book double time slot. This reduces the chance of the dentist running late and provides enough time not to feel rushed.

* Social stories™

Social stories are an effective way of providing information to an individual about an activity and the reason for doing it. A social story could be a good way of helping an individual to understand what happens at the dentist and why we need to go to the dentist. For further information please see the autism helpline information sheet on social stories and comic strip conversations.

* Story books

There are lots of basic story books about visiting the dentist these may also help. For example Topsy and Tim go to the dentist

* Breaking down the visit using visual supports

It may be useful to try and produce a sequence of pictures or photo's to show the stages of going to the dentist. This allows you to cover up the different steps so they know what is coming next and when it is finished. You may wish to include a reward picture at the end of the sequence so they have something to look forward too.

* Time indicators

Helping them to realise that this experience does have a time limit is important. By using visual (sand timer) or auditory timers (buzzer, watch alarm) they can have an understanding and monitor the time of the experience.

* Comforters/distracters

Letting them take comforters could help occupy them and or distract them. For some taking a walkman or having music on can act as a good blocker.

* Sedation

For some the experience is so distressing that they may need to consider sedating them. If you feel this is the case you need to talk through with your dentist and a medical professional to discuss the options.

* Professional input

There are some dentists who specifically see individuals with special needs, see below for different types of dentists.

General dentist

Some general dentists have experience and work with people with additional needs.

Community Dental service

Are specially trained dentists who work within the community within homes and schools.

Hospital dentist

Dentists who work within a hospital setting you would require a referral from either a general dentist or the community dental service to access them.

For details of dentists with special needs experience:

England

NHS Direct 0845 46 47

<http://www.nhs.uk/England/Dentists/Default.aspx>

Wales

NHS Direct 0845 46 47

<http://www.nhsdirect.wales.nhs.uk/nhsdirect.asp?id=227>

Scotland

Either contact your local health authority or the following link gives a general list but not special needs specific.

<http://www.dentalguide.co.uk/index.html>

Further Contact:

The British Society for Disability and Oral Health

The Dental Department
Royal Leamington Spa Rehabilitation Hospital
Heathcote Lane
Leamington Spa
Warwickshire
CV34 6SR

Tel: 01926 317726

Web: www.bsdh.org.uk

Resources:

Adamson, J. (2003) *Topsy and Tim go to the Dentist*, Penguin UK

Green, J. (1999) *Open Wide! - My first trip to the dentist* Wayland publishers Ltd: UK

Rowan, K. (1999) *I Know why I brush my teeth* Walker Books: UK

Smith, A. and Tatchel, J. (1998) *Flip Flap Body Book* Usborne Publishing: UK

If an item is marked as available from the NAS please contact:

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Appendix c – the view from outside the UK

Sixty-six parents completed our survey who did not live in the UK. Whilst we have excluded their responses from the main body of the survey, we felt that we should not ignore their views. 43 of them had not used NHS dentistry at all. The remaining 23 had used it – we do not know whether these respondents used to be UK residents now living abroad or were nationals of for example, Eire, or other foreign nationals who had come to the UK and used dental services, perhaps in an emergency.

Of those who had expressed an opinion of the NHS, six were very satisfied, two quite satisfied, four had had some problems, one was quite dissatisfied and three were very dissatisfied.

Ten said they had had problems finding a regular dentist, eight an emergency dentist, five had had problems finding a sympathetic dentist, eight had used private dentistry, five had gone without treatment and six had had physical accessibility issues. Thirty-five had experienced none of these.

Thirty-nine had no experience of the forms of care we specified. Eight had used hospital care, 11 a mobile unit at school, four had had a home visit and eight had used the community dental service at a clinic.

As we know nothing of their situation, we have not attempted to draw any conclusions from these results.

contact a family
for families with disabled children

Getting in contact with us

Freephone helpline for parents and carers

0808 808 3555

Access to over 170 languages

www.cafamily.org.uk

www.makingcontact.org