



Здоровье полости рта взрослых с ограниченными возможностями обучения в Шеффилде, 2011 г.

Автономная некоммерческая
организация «Все дети могут»



www.vsedetimogut.ru

The Oral Health of Adults with Learning Disabilities in Sheffield 2011

Research and report conducted and compiled by Academic Unit of Dental
Public Health, University of Sheffield.



Acknowledgements

This research was carried out by The University of Sheffield from October 2010 to May 2011. The research team comprised of Dr Melanie Hall, Dr Zoe Marshman and Dr Janine Owens.

We would like to firstly thank NHS Sheffield for funding this project which in the field of dentistry is the first project to apply inclusive methods as a way of enabling people with learning disabilities to have their voices heard about their care. Secondly we would like to thank people with learning disabilities and their supporters without whom the study would not have been possible. Thirdly, our thanks are extended to 'Signpost Sheffield' who enabled our development of an inclusive questionnaire.

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Executive Summary

The aims of this research were to:

- Investigate, using a postal survey, the oral health and dental service use of adults with learning disabilities in Sheffield
- Explore the experiences and perceptions of dental services of people with learning disabilities in the Sheffield area

The aims were achieved by representing the voices of people with learning disabilities through different research approaches.

Adults with learning disabilities are now more frequent consumers of healthcare, and because of technological advancements in modern medicine coupled with improved living and nutrition are living longer. With a change in policy, fewer people with learning disabilities now live in institutions and instead are housed in the community in a variety of ways; from small group homes to sharing with a friend or partner, to living alone with a minimum of support.

This change in ways of living has required changes in how healthcare services are accessed and structured. Even when people with learning disabilities were institutionalised it was noted that their healthcare needs were often greater and their health was frequently reported as being poorer than people without learning disabilities. Oral health is no exception with the oral health status of adults with learning disabilities being reported as poorer than that of the general population, with the distribution of dental diseases in this group of people still remaining unclear.

Within the field of dentistry the inclusion of the voices of people with learning disabilities has been noticeably absent. Perceptions, opinions, experiences, and indeed how choices and decisions are made have been unaddressed by dental research. Moreover, whilst national surveys of the dental health of adults have been undertaken every ten years since 1968 in England and Wales and in the whole of the UK in 1978, 1998 and 2009, people with learning disabilities have often been excluded from these surveys.

To address these issues two forms of research were needed:

1. **Quantitative:** A questionnaire that mirrored the questions used in national and regional postal surveys for the general population.
2. **Qualitative:** Research that enabled people with learning disabilities to have their voices, beliefs and experiences heard directly.

The quantitative study

A questionnaire was developed from the 2008 Yorkshire and Humber postal questionnaire of oral health and experiences of dental services. An easy read version was also developed to enable people with learning disabilities and their supporters where applicable, to complete the questionnaire. A random sample of 2000 people on the Sheffield learning disabilities case register was sent the questionnaire and easy read version. Only one mailing was used, 628 people returned the questionnaire.

This was the first postal survey of the oral health of adults with learning disabilities in the UK. Although the response rate appeared low (31.4%) this was equivalent to other surveys of the general population with only one mailing. We found that the self-reported oral health status for adults with learning disabilities was equivalent to other local and national surveys in terms of oral health and service use.

Specifically:

- ❖ The self-reported number of teeth among adults with learning disabilities in Sheffield is similar to that reported by adults in the general population in Sheffield.
- ❖ Lower numbers of adults with learning disabilities are wearing dentures.
- ❖ People with learning disabilities reported poorer overall oral health although specific impacts of pain, discomfort when eating, and self-consciousness, were similar to or of lower frequency to existing surveys.
- ❖ The reasons for visiting a dentist were similar to surveys of the general population. However, reasons for difficulty with getting dental care varied with dental anxiety and transport problems being more prevalent for people with learning disabilities.
- ❖ Transitions between children and adult services were highlighted as being problematic.
- ❖ There were more issues regarding access to care for people with more profound impairments.

The qualitative study

After discussion with self-advocacy and learning disability groups, a mixture of five focus groups and one-to-one interviews were used as a means of exploring the oral health experiences of people with learning disabilities. All encounters were audio taped. The total number of people interviewed was 30. One researcher with expertise in working with people with learning disabilities carried out the interviewing and transcribing. Those interviewed accessed a variety of dental services in the Sheffield area; from private, to NHS, and salaried dental services. The

majority of people lived in supported tenancies, a few lived independently with little or no support and a minority lived in community homes.

Access to services proved to be a problem and there were aspects of care quality linked to access. Issues such as transport when a carer had no means of taking an individual to their appointment, and physically getting an appointment was problematic in some areas with some clinics heavily booked and over subscribed. Changes from NHS to private practice by some dentists in Sheffield and the surrounding areas had left some people without a dentist. Moving from one area to another and then being unable to travel back to a previous area because of transport difficulties and being unable to find a practitioner in the new area were other issues raised. There were also examples of people with learning disabilities having to take what they were given and being left with little or no choice as to the type of services they received.

Recommendations

This was the first dental study that involved people with learning disabilities in identifying gaps in service provision. Recommendations from both strands of work were:

- Further support for and education of carers in oral care
- Disability awareness training for qualified dentists and undergraduate students
- The need for appropriate information to be developed for groups, carers and individuals
- Improvements to the design of services to ensure seamless care for all people with learning disabilities during transition to adulthood and change of residence.

The full report which follows begins with the background to the project and then separates the quantitative and qualitative strands. Overall recommendations are then provided.

1.0 Introduction

The aims of this research were to:

- Investigate, using a postal survey, the oral health and dental service use of adults with learning disabilities in Sheffield
- Explore the experiences and perceptions of dental services of people with learning disabilities in the Sheffield area

The aims were achieved by representing the voices of people with learning disabilities through different research approaches.

Adults with learning disabilities are perhaps the largest underserved population globally experiencing inequities in health access and outcomes (Lollar and Andresen 2011). They have become more frequent consumers of healthcare because with advances in medical and assistive technology, and rises in the standard of living and better nutrition they are living longer (Beange 2002). With the introduction of National Health Service Community Care Acts (1990, 1998) and Health and Social Care Act (2008) fewer people with learning disabilities now live in institutions. This means that they can now access a greater variety of healthcare services. With this dramatic increase in life expectancy there has also been a greater need for availability of health services. Availability of high quality oral healthcare services are important because oral health influences psychological well being and satisfaction (Locker *et al.*, 2000, Persson *et al.*, 2009, Christensen *et al.*, 2011) in the general population and there is no reason to suggest that there is any difference for people with learning disabilities.

Dental treatment needs of adults with learning disabilities are usually greater than those of the general population with reports of poorer oral hygiene (Cumella *et al.*, 2000); more periodontal disease (Sigal 2010) and untreated dental caries and more teeth treated by extraction than for the general population (Tiller *et al.*, 2001). Greater oral health needs have been reported for institutionalised people with learning disabilities (Crowley *et al.*, 2003), with suggestions that oral health may suffer when people are moved from institutionalised to independent living because of the greater availability of foods and drinks that can cause dental decay (Stanfield *et al.*, 2003). One factor implicated in treatment need for adults with learning disabilities is the interrelationship between oral disease and systemic disease, which can create greater oral health inequalities for some people with learning disabilities (Prasher and Janicki 2002).

National surveys of the dental health of adults have been undertaken every ten years since 1968 in England and Wales and in the whole of the UK in 1978, 1998 and 2009. However, few surveys have considered the oral health of adults with learning disabilities. Previous surveys have focused on normative assessment of clinical status (Davies *et al.*, 2008) or changes from institutional living to community-based housing (Stanfield *et al.*, 2003, Tiller *et al.*, 2001). In 2001, a survey of the oral health status and dental service use of adults with learning disabilities in Sheffield found participants living in the community were less likely to have a dentist than those in residential care (Tiller *et al.*, 2001).

In recent years, there has been a growing emphasis on encouraging service users to offer their views on the services they receive, but people with learning disabilities are more likely to be viewed as passive recipients rather than active participators (Lowe 1992). With the development of self-advocacy and recent progress in health policy (Department of Health 2003, 2004, 2007a, 2007b) and more specifically 'Valuing People' (Department of Health 2001), people with learning disabilities are now regarded as informative, critical and reliable service evaluators (Kroese *et al.*, 1998). However, to date, no studies have directly investigated the impact of oral health on the daily lives of people with learning disabilities, their perceived need for treatment, or reasons for difficulties with access to a dentist.

Within dentistry there has been a paucity of research that has included the voices of people with learning disabilities, a recent systematic review indicated that in dentistry people with learning disabilities are routinely excluded from research that concerns them and research is usually done 'on' them, rather than 'with' them (Whelan *et al.*, 2010).

What follows are the two strands of the research; quantitative and qualitative with overall recommendations at the end.

2.0 Quantitative Strand

The aim of the quantitative strand was to investigate the oral health and dental service use of adults with learning disabilities in Sheffield through the use of a postal questionnaire.

2.1 Questionnaire

To allow comparison, the questionnaire used was developed from the questionnaire used in the regional postal survey in 2008 (Yorkshire and Humber PHO 2009) and included:

- self-reported oral health status and the impact of the mouth on everyday life
- experience of using oral health services
- estimate of the demand for dental care

The format and wording of questions were amended slightly to make it more user-friendly for people with learning disabilities, and guided by previous research indicating that photographs increase the frequency of responses (March 1992, Norah Fry Research Centre 2004) an accompanying explanation sheet was developed with 'Signpost Sheffield' who regularly produce easy read documents. The easy read version used pictures to enable completion either directly by people with learning disabilities or for people with learning disabilities to be included in its completion with the help of their supporters or carers (Appendix A).

2.2 Ethical and research governance procedures

Ethical approval was provided by Sheffield Research Ethics Committee and research governance approval was received from NHS Sheffield.

2.3 Sample size

Key information required by NHS Sheffield included the proportion of participants that had difficulty accessing dental services and those perceiving they needed dental care. Earlier UK studies reported 15% of adults had difficulty with access (Robinson et al., 1998) and 25% perceived they needed treatment (Kelly et al., 1998). Based on these data, precision estimates indicated an intended sample of 1080 participants would provide 95% confidence that the population proportion would be 15% +/- 6% (access difficulties) and 25% +/-7% (perceived need for treatment). This level of precision was regarded as acceptable.

Health and lifestyle surveys achieve variable response rates (Owen-Smith et al., 2008). Assuming 50% of those sampled would not respond, an intended sample of approximately 2000 participants was estimated.

2.4 Sampling

The accessible population included all adults (aged 18 and over) on the Sheffield learning disabilities case register (n=3080). A random sample of 2000 people was taken by the Sheffield learning disabilities case register team.

2.5 Method

Where possible, the survey used methods identified as maximizing response rates (Edwards et al., 2007). Questionnaires and appropriate covering letters were posted to the selected individuals inviting them to participate. Stamped addressed envelopes were provided. Only one mailing was used. The names and addresses were added to the envelopes by the Sheffield learning disabilities case register team to ensure confidentiality.

2.6 Analysis

Descriptive statistics were produced for responses to each question. Data were analysed using SPSS v. 17 (Statistical Package for the Social Sciences).

Although postcodes were obtained, analysis on the basis of deprivation was not conducted due to the frequently enforced moves from area to area experienced by many people with learning disabilities (Barnes and Mercer 2010).

2.7 Results

2.7.1 Responses to the survey

Response rates

Of the 2000 questionnaires mailed 117 were returned by the post office and 628 were returned completed, representing a response rate of 31.4%. This response rate is similar to that achieved by other lifestyle surveys (Owen-Smith et al., 2008). Over one quarter (27.7%) were completed by the individual, 30.9% by a paid carer, 23.4% by an unpaid carer and 17.4% were completed by someone else.

Demographic information

Of the 628 who responded, 353 (56.2%) were male and 272 (43.3%) were female. Table 1 shows the age profile of participants. The mean age was 40.2 years and ranged from 18 to 87 years.

Table 1. Age profile of participants (n = 623)

Age Group (yrs)	Percentage (%)
18-24	20.3
25-34	19.7
35-44	21.4
45-54	19.6
55-64	10.9
65-74	5.9
75 and over	1.7

The majority (91.1%) described themselves as White British, 2.4% described themselves as Pakistani, 1.4% described themselves as mixed White and Black Caribbean and 1.0% described themselves as Black Caribbean.

2.7.2 Number of teeth and denture wearing

Number of teeth

Oral health status was assessed simply by asking participants whether they had natural teeth, and if so, how many natural teeth they had remaining. Overall 93.6% of participants had one or more natural teeth. In 2009, 94% of UK adults had one or more natural teeth (Steele et al., 2011), in 2008 93.3% of adults in Sheffield had one or more teeth. Of those participants with no natural teeth, 46.1% were 65 years and older.

Denture wearing

Approximately one tenth (11.5%) reported wearing an upper denture and 7.2% wore a lower denture replacing some or all of their natural teeth. This is lower than the 2008 data from Sheffield which found 21.1% and 12.1% of adults wore a upper and lower denture respectively.

2.7.3 Impact of the mouth on everyday life

The questionnaire enquired about the impact of the mouth on everyday life. The first question was concerned with the overall health of the teeth, lips, jaws and mouth. A further three questions asked

about the impact of oral health in terms of the frequency, in the last 12 months, of pain, discomfort when eating and being self-conscious.

Self-reported oral health

Approximately a third (31.2%) of adults stated their oral health was fair, poor or very poor. This was higher than the results from the 2008 survey of adults in Sheffield of 23.8%.

Pain in the mouth

The percentage of participants reporting a painful aching in their mouths occasionally or more often in the last 12 months was 27.7%. These data are similar to that from the UK Adult Dental Health Survey where 30% reported occasional or more frequent pain (Steele et al., 2011) and from Sheffield data where 30.8% reported such pain.

Discomfort when eating

Approximately one quarter of participants (26.6%) reported occasional or more frequent discomfort when eating because of problems with their teeth, mouth or dentures in the last 12 months. The UK Adult Dental Health Survey in 2009 found 30% of participants reporting occasional or more frequent discomfort when eating (Steele et al., 2011) compared to 33.8% for adults in Sheffield.

Self-consciousness

Overall, 13.1% of participants reported being self-conscious occasionally or more often in the last 12 months because of their teeth, mouth or dentures. The UK Adult Dental Health Survey reported 19% of adults being self-conscious about their mouths occasionally or more often (Steele et al 2011). In 2008, 29.9% of adults reported self-consciousness.

2.7.4 Perceived need for dental treatment

A fifth of participants (19.3%) felt they needed dental treatment and 34.7% did not know whether they needed treatment, compared to 22.1% in Sheffield who felt they needed treatment and 25.5% who did not know.

2.7.5 Dental attendance

The questionnaire included items on the length of time since last visit to the dentist, reasons for dental attendance and difficulty obtaining dental care. The National Institute for Health and Clinical Excellence (NICE) guidelines state that adults should see a dentist at least once every two years (NICE, 2004).

Time since last visit to the dentist

Overall 86.0% of participants reported attending the dentist within the past two years, 4.0% attended between two and five years ago, 7.5% more than five years ago and 1.9% reported never attending. The survey of adults in Sheffield in 2008 found 83.5% reported attending in the past two years. Data from the Information Centre (derived from FP17 forms submitted by dental practices) reported 61.8% of adults in Sheffield had seen an NHS dentist in the 24 months prior to the end of June 2010 (Information Centre, 2011).

2.7.6 Reasons for visiting the dentist

Overall, the most frequently reported reason for visiting the dentist was to have a regular dental check-up (74.7%). About a tenth of participants (11.6%) only attended when they were having trouble, and 3.3% had never been to the dentist. These figures are similar to the data from Sheffield in 2008 where 72.3% went for regular check-ups, 16.9% attended only when having problems and 3.2% had never been.

2.8 Access to Services

2.8.1 Difficulties getting routine care

Difficulties gaining access to routine dental care were reported by 13.2% of participants compared to 19.5% in Sheffield in 2008. The most commonly reported reason for difficulties were 'scared of dentists', 'difficult to make the journey to the dentist' and 'no local dentist'. These reasons were different from those most commonly reported by adults in Sheffield in 2008 of 'treatment too expensive', 'dentists only treating privately' and 'no dentists taking patients'.

2.8.2 Difficulties with access when having problems

The questionnaire also enquired about difficulties accessing dental care when people were having problems with their teeth or mouths. Overall 10.5% of participants reported having such difficulties compared to 16.0% in Sheffield in 2008. As with access to routine care, the most frequently reported barriers to care when having problems were 'scared of dentists' and 'difficult to make the journey to the dentist'.

2.8.3 Other sources of help

Of those participants reporting difficulty getting dental care, the most frequent other sources of help were the doctor, Charles Clifford Dental Hospital, family and support workers.

2.8.4 Other written comments from participants

Participants were asked for any other comments about their oral health or service use. People with learning disabilities cited reliance on carers to accompany them to appointments or even making an appointment as both beneficial and simultaneously a barrier. Other comments related to problems with access; lack of availability of NHS dentists and the length of time it takes to get an appointment, privatisation of existing services and being unable to afford to attend. There were also difficulties carrying out oral hygiene practices. Positive comments were also made:

'Dentist knows of my learning difficulties. This is important to me as he explains things in a way I can understand.'

'Overall my teeth are v good. Because of work I only make appointments on a Friday but my dentist is v good. Excellent!'

Supporters and carers cited a lack of tolerance of dental treatment from people with learning disabilities, and being unable to tell when they were in pain because some people lacked verbal articulacy and the ability to communicate pain.

'I'm the mom of the person with difficulties in this Questionnaire. He has got no communication skills and I constantly worry whether he has toothache and I wouldn't know. We tried to sedate him last time for a good look round but the amount usually used didn't touch him.'

They also discussed the lack of disability awareness from some members of the dental team;

'Some dentists are better than others at treating people with disabilities. Receptionists do not always understand. As a parent, I can negotiate the system. I found an NHS dentist locally, a person with disabilities could not possibly have done this. My daughter certainly could not' [parent].

One issue was a lack of information about how to change dentist and inconsistencies in referral procedures:

'Not happy with local dentist. Unable to get appointment at Firth Park Clinic despite referral by GP. Had to go privately to get replacement dentures when I broke mine. We had problems trying to access dental care for adults with learning disability. Little information available on how to do this.'

'Need a lot of support. Would like dentist of same gender. Need preparation and info that is clear. Very hard to change dentists/venues. Highly anxious.'

Other issues surrounded people with more profound impairments needing in-patient procedures with waiting times were cited as excessive:

'People with a severe learning disability need hospital admission for treatment. Although the service is excellent the length of waiting time for an appointment is much too long.'

'If treatment needed like having a filling or tooth out too long a waiting list time because anaesthetist needed for sedation and by the time you get to the dentist the tooth has to be taken out, where maybe it could have been filled if you didn't have to wait as long.'

'Currently waiting to have a filling. may have to wait 4-5 months for this as the only way of doing it is to get a general anaesthetic. Being autistic, he won't co-operate with treatment.' [father]

Issues were cited around transition of care by both people with learning disabilities and their carers:

'I regularly went to dentist before I went to residential college in Kent. The college won't take me to the dentist. I haven't had time to look for a dentist in Sheffield since my family moved there two years ago.'

'The special needs children's dental service was fantastic. However, the adult service seems very understaffed.'

Supporters and carers disliked the lack of choice of treatment and services for people with learning disabilities:

'Local dentists don't seem confident to see people with disabilities. Only dentists who visit special schools can. People with disabilities should have the right to have treatment to their teeth e.g. I need straightening or any cosmetic dentistry. Our experience with most dentists is that they do not feel competent or comfortable when dealing with disabled people which in our view is tantamount to discrimination.'

2.9 Summary

- This is the first postal survey of the oral health of adults with learning disabilities in the UK. Although the response rate appeared low (31.4%) this was equivalent to other surveys of the general population with only one mailing.
- These findings for adults with learning disabilities are equivalent to other local and national surveys in terms of oral health and service use:
 - The self-reported number of teeth among adults with learning disabilities in Sheffield is similar to that reported by adults in the general survey in Sheffield.
 - Lower numbers of adults with learning disabilities are wearing dentures compared to the general population.
 - People with learning disabilities reported poorer overall oral health compared to the general population although specific impacts of pain, discomfort eating and self-consciousness were similar or of lower frequency in those with learning disabilities.
 - The reasons for visiting a dentist were similar between those with learning disabilities and those in the general population. However, reasons for difficulty with obtaining dental care varied with dental anxiety and transport problems being more prevalent in those with learning disabilities.
 - Transitions between children and adult services were highlighted as being problematic.

- There were more issues regarding access to care for people with more profound impairments.

3.0 Qualitative strand

The qualitative strand aims to represent the voices of people with learning disabilities whilst exploring their experiences and perceptions of dental services in the Sheffield area.

3.1 Methods

To explore the oral health experiences of adults with learning disabilities qualitative methodologies were employed. Although the study was an ethnographic exploration it employed narrative and narrative methods as the framework for thinking about experiences in multiple but related ways. This approach is rooted in symbolic interactionism and phenomenology which, when joined with ethnography lend a theoretical background to the style of research. Symbolic interactionism assumes the need to examine the subjective experiences of adults with learning disabilities in order to understand and describe their symbolic world. Simultaneously, phenomenology emphasises people's immediate experiences and current relationships, perceptions and encounters. Blending these three research paradigms means taking an interpretive approach, and interpretation of the social life of people is firmly rooted in ethnography.

This section of the report concentrates exclusively on the experiences of adults with learning disabilities from their perspective. The names and details of the people involved have been altered to protect their anonymity.

3.1.1 *Establishing contact*

One researcher with experience of working and conducting research with adults with mild to profound learning disabilities made contact with the numerous self advocacy groups and independent advocates in the Sheffield area, attended health fairs, the People's Parliament, liaised with Signpost Sheffield, Sheffield Health and Social Care NHS Foundation Trust, the Learning Disability Partnership Board, community learning disability teams, the expert patient group, Mencap, and independent living teams and networks. Fliers were distributed to stimulate discussion and small presentations given to raise awareness of the research. People with learning difficulties were then given time to discuss with one another, and their supporters, as to whether they wished to take part in the research, and to indicate if they preferred focus groups or one-to-one interviews. All areas visited provided a group, or one-to-one, or gave verbal feedback through their supporters.

3.1.2 People in the aggregate: the sample

A purposive sample of thirty people with learning difficulties who self-selected was employed. The age ranged from twenty-one to seventy-five years. All respondents lived in the Sheffield area. Of the thirty people, five lived in registered care homes, fifteen had supported tenancies where permanent staff carers provided twenty-four hour support, and the remaining ten lived independently in the community with varying levels of support. All respondents were regular users of dental services in the Sheffield area; utilising a mixture of private, NHS and salaried dental services. One person reported having a Black ethnic background; the remaining respondents reported a White ethnic background.

3.1.3 Focus Groups and interviews

Four focus groups and one one-to-one interview took place, each one hour in length. The focus groups consisted of five to eight people per group and included their supporters where necessary. The supporters knew how people communicated and were invaluable facilitators in having their client's views heard. Six appeared to be an ideal group number and many people in the groups knew one another and already had a bond which undoubtedly helped the group dynamics. The majority of the groups were articulate and for those who lacked, or were poor at, verbal articulation their supporters were a necessary resource to their inclusion. The questioning was open, and people were encouraged to discuss from their own perspective about their oral health experiences, probes were used when areas of interest for the groups arose and discussion became intense, closed questions were used to facilitate interactions with people who were less articulate.

All encounters were taped and transcribed verbatim. To assist with transcription and contextualisation, extensive field notes provided important elements related to each setting. These field notes were invaluable when transcribing tapes where verbal articulacy was unclear because some respondents had speech impediments which did not lend themselves effectively to tape recording. Previous extensive experience in the field working and researching with people with learning disabilities meant that the researcher had developed a habit of echoing what was being said to clarify that she had understood, and to record the utterances on tape with greater clarity. Non-verbal communication was also used, for example Makaton or nods and hand movements to indicate agreement, disagreement, or the desire to participate. Field notes and researcher experience, alongside the use of narrative methods, were invaluable to broaden the context of the encounters.

3.1.4 Analysis

An inductive qualitative analysis took place. This process was iterative and progressive because it repeated itself throughout the research from initial awareness raising talks about the research, the interviews and focus groups, transcribing the data, re-reading the field notes and the transcribed data. The process involved noticing recurring patterns and themes throughout the process, as everything was broken down into manageable pieces, and then reassembled to form a reconstituted narrative incorporating the voices of people with learning disabilities.

3.1.5 Results

The results highlighted the main theme of access which mapped onto dimensions of a blended model of access (Penchansky and Thomas 1981) and quality (Donabedian 2003), [for further discussion see Owens *et al.*, 2011]. The dimensions are:

- Accommodation
- Affordability
- Appropriateness
- Availability
- Accessibility
- Acceptability

These dimensions are not mutually exclusive and in the examples that follow there is inevitably some cross over.

3.2 Access: Accommodation

Accommodation refers to how easy it is for the patient to ‘get through the door’; this may mean opening times, flexibility of and waiting times when making appointments, ease of transit through bureaucracy which includes form filling and procedures. It also acknowledges that there may be a gatekeeper to access; for example, a carer or supporter of an adult with learning disabilities.

3.2.1 Obtaining appointments

Many people talked about how they obtained appointments to see a dentist this ranged from: FG2 Peter: ‘[...] they send me a card’

This is for a regular check-up every 6 months, and Peter relies on the dental practice to send him a reminder.

FG2 Emma: *'It's in the diary and the nurses sort it'.*

For Emma, her supporters take control over her oral health care and note when she needs another appointment.

FG1 Kate: *'I go on my own and I sort it out myself'.*

Kate lives independently in the community and makes her own appointments with her GDP.

FG3 Alan: *'They don't send a card through I have to remember when to go, but my supporters sort it out, they write in the diary when they need to phone up for another appointment.'*

Alan lives in supported accommodation and his supporters enable him by keeping a diary of when he needs to attend for appointments at his local GDP.

FG 1 Arthur: *'I used to live with my mum but she died and I'm somewhere else now and I have to wait to see the dentist because I don't live near anymore.'*

Living circumstances can change quickly for some people with learning disabilities, particularly when a carer dies suddenly. Arthur lost his social support network overnight, along with a dentist whom he had grown to trust. He is now struggling to find someone who will treat him and with whom he can build a similar relationship.

FG 2Carer: *'A lot of people go to the dental clinic for people with learning disabilities, the only thing I find is that they don't get the appointments as often as they should because they are so busy.'*

This carer is pointedly saying that the community clinics are so busy that often appointments are delayed.

FG1 Carer: *'[...] it's like that for all Sheffield if you go to a community clinic. It's bad trying to get an appointment. Having one clinic do the same amount of work compared to a lot of people like there were in the past.'*

This carer reinforces what the carer in another group has said and suggests that the issue has become more problematic over time.

FG1 Sarah: *'I pulled it out myself'*

FG1 Sarah's carer: *'She had an appointment but it was so loose, she is due to go to the clinic but it is so difficult to get though.'*

Sarah has periodontal disease and her tooth was so loose she pulled it out herself; her carer reports that it is difficult to get through to her local community clinic to obtain an appointment.

3.3 Access: Availability and Affordability

This refers to the volume and type of services that enable choice and inclusion, and the cost of and ability to pay for services.

3.3.1 Entry to services and paying for treatment

FG5 Andy: *'Do you know how to get a dentist because I have moved and my carer does not know what to do?'*

Andy has problems accessing services to obtain an appointment because he has moved areas and his supporters do not know how to enrol him for dental care. He has been to three NHS practices independently but their lists are all closed. The local community clinic only takes referrals and his supporter is unsure as to how to proceed.

FG 5 Susie: *'[...] mine went private and now I don't have one and then I went to see someone else who said they could see me but it gets difficult if they are booked up.'*

Susie lives independently and has managed to find a new dentist but getting an appointment is difficult because her dentist is booked a month in advance.

FG 4 Cathy: *'[...] I can't go back to my old dentist because it's too far since I moved to Sheffield and my friend's dentists are all full. I need someone in South Yorkshire if I need treatment because of my medical problems. I don't think a private place would take me, not that I can afford or want to go private, it's just that they are all going private and that stops me choosing where I want to go. Even if you have been going for years and they go private what can you do?'*

Cathy is experiencing difficulty obtaining an NHS dentist after moving here from Derbyshire. Her old dentist is two hours away by 3 different buses and she feels that this journey is too much for her. It would be possible for her to find a dentist in Sheffield if she had some support.

Summary

The range of experiences discussed by people with learning disabilities illustrates that there are issues for some people in relation to the accommodation and availability of treatment. Salaried dental services were often busy and over booked, and if a sudden area move occurs the loss of social support often meant that there was no continuity of care for dental treatment. This links to the volume and type of services available thereby enabling choice and inclusion for people with learning disabilities.

3.4 Access: Accessibility

This refers to the physical means by which the patient reaches the services. This can refer to the distance travelled, and/or barriers to travel experienced, and the proportion of primary care services accepting people with learning disabilities for treatment.

3.4.1 Travel

The process of getting to the dentist can prove an issue for some people with more moderate or profound learning disabilities and/or physical impairments.

FG3 Pam: *'I had trouble getting to the dentist but they send a taxi now.'*

FG3 Sid: *'It's a long drive and then we have to wait and the dentist can take a long time.'*

FG2 Lorraine: *'I go to the dentist but I have to wait for my car to take me and if my helper has no car I can't go.'*

FG 2 Carer: *'Many clients struggle because it depends how mobile they are, for some it would help if someone could visit them in their own home.'*

FG4 Carer: *'The clinic where we go is 2 bus rides away and if you haven't got a car it's a problem.'*

FG1 Sam: *'It takes a long time to travel there and it hurts when I go; the dentist is a bit scary and it scares me.'*

FG3 Bridget: *'I went to the dentist with my mum and it was too long to travel, the dentist is alright but I'm scared.'*

Summary

Physical access may prove to be an issue for some people with learning difficulties who require additional support with mobility. Salaried dental services are not always easy to access without transport and other forms of care may be more effective at enabling physical access. Travelling for an extended period of time when frightened may increase anxiety levels making treatment more problematic for both dentist and patient alike.

3.5 Access: Acceptability

This refers to the level of satisfaction expressed by the patient and revolves around what makes a treatment experience satisfactory for the patient. This area generated the greatest number of interactions with people with learning disabilities and included people with limited or no verbal articulation indicating how satisfied they were with their care.

3.5.1 Experiences of treatment

There was a mixture of good and bad experiences of treatment; some experiences revolved around pain, others around treating people with dignity, some experiences were shrouded in fear, and others reflected a positive approach by practitioners which had enabled their patients.

FG 5 Mikey: *'I went a few weeks ago and I had pain and I had to have a tooth out and he took it out and it hurt after 3 days and I had to have tablets to stop it hurting.'*

Mikey unfortunately had a dry socket after his extraction and had antibiotics, he was a regular attendee at the local salaried dental service but he noticed the variation in his care:

'I go to the clinic dentist and he is nice, he talks about everything and he tells me what he is doing and everything. I didn't like the other man I went to see because he only talked to me when he was doing something.'

Mikey contrasts how his recent dentist makes him feel included in his treatment, compared to his previous dentist.

FG5 Steve: *'[...] sometimes if you can't explain to them you just go and sit in the chair and you have no idea what is happening, then you get worried and think what can I do?'*

Steve had a bad experience with a dentist who failed to explain about what can happen with local anaesthetic if injected into a vein in error. He ended up with tachycardia, was terrified, lost control and became aggressive. He attended alone without a supporter and was reappointed but asked that he was warned of what might happen in future just so he could prepare himself. The experience has left him wary of dental treatment. Being able to prepare yourself and knowing what to expect was quite important for many people, Kay was especially vocal:

JO: *'Does it help a lot having it explained?'*

Kay: *'Yes, you know what you are having done and what it involves; you can say 'I'm going into hospital overnight and having this done'. Also if you are on the autistic spectrum and if you have Aspergers we like any procedure explained to us so we know what it involves. The more clear people are in what is going to be involved the more we can prepare. [...] getting to know you and your fears and worries, being clear, I mean being clear is vital because if you don't know what is going on it can cause anxieties, and if it involves more complex work that gets others involved then be clear how and when this will happen. Clear communication [...]*

Penny's experiences contrast with Kay's advice and illustrate the lack of dignity afforded to her when she attends for treatment:

FG1 Penny: *'When I go my dentist talks to my supporters, not to me. He don't talk to me and tells me what he is doing, I can speak, I can say yes and no but he just don't ask me what I want.'*

FG2 Carer: *'With autism in particular that face is important and knowing the place is important. It is important to build that relationship with someone so that treatment can go smoothly...you know you can't just expect a stranger to enter your life and tell you what to do. Our clients have to put up with this approach; it's very much sit there and shut up if you'll forgive my language.'*

This carer emphasises the importance of continuity and hints that in some contexts people with learning difficulties are objectified, with little regard for their rights as citizens. This reflects Penny's experiences of dental care.

Fred has attended the same dental practice since he was three, albeit under different practitioners:

FG1 Fred: *'[...]I've been with the same dentist because I don't like changing when we move so I kept mine [...] he knows me and my dental history and I feel happy with him [...] I stayed because I knew it would be hard to find and NHS dentist so I said I would stop with him. [...] I like him because my dentist tells me what he is doing.'*

Fred has built a relationship of trust with his dentist over the years, this and the knowledge of the difficulties in obtaining an NHS dentist has influenced him to stay with the same practice.

Tommy felt the same and using Makaton indicated that years ago he did not like going to the dentist, but as he got used to going he saw the same face and this made him feel safe. This indicated that continuity of care was important for many people with learning disabilities. Diana

indicated through nods and moans that she liked knowing where she was going and she liked to see the same people.

FG1 Pam: *'I've got my own dentist and he's great, he's my dad's dentist and I go with my dad, I like going.'*

Pam was also quite happy to attend the family dentist and has been doing so for the past 15 years.

Summary

Even if people with learning disabilities are frightened of treatment it becomes more bearable if they have the continuity of a familiar face who explains the stages of their treatment to them. They want to be treated with dignity and included in choices and decisions about their treatment wherever possible.

3.5.2 The 'proper dentist'

Throughout the course of the focus groups the phrase 'proper dentist' emerged. When probed, the responses from people with learning difficulties mostly centred on communication and interpersonal skills which they felt a 'proper dentist' should possess.

FG1 Rosa: *'It's going to a proper dentist that is important'*

JO: *'What makes a proper dentist does everyone think?'*

Rosa: *'Well one that can do all your treatment and doesn't have to send you somewhere else, unless it is too difficult or you have to go to sleep, like when I went to the clinic they couldn't do some of the work that my dentist can do, so does that mean they are not proper?'*

Ruth: *'One that talks to you and listens and can tell you what they are doing so you can understand'*

Alan: *'One that is nice and doesn't hurt'*

Lizzie: *'One that isn't too busy to see you and spends time with you'*

Sam: *'One that talks to you and not the person with you'*

Helen: *'I've got learning difficulties and I understand what they are saying, I just speak slowly and it sometimes takes me a long time to think about what they are saying and decide what I want doing. I just need a bit of time to think, like it has taken me a while to say this but I sat and thought first.'*

FG5 Steve: [...] *'I went to a proper dentist'*

JO: *'That's interesting, what makes a proper dentist?'*

Susie: *'It's how they treat you really'*

Andy: *'A dentist that doesn't cause you pain'*

Mikey: *'One that tells you what's happening and what they are going to do.'*

Pete: *'A dentist might say what they are going to do and then they need to tell you again in case you don't understand'*

Mikey: *'They tell you what they are going to do and talk all through as they are doing something so I know what is coming and I am not scared.'*

Andy: *'Mine does the same; he tells me, and he shows me what he is going to do and then step by step so I know what is happening and I know what to expect. I find it easier for me because I am following what he is doing and I feel in control.'*

JO: *'Does that make you feel safer if he is explaining?'*

Chorus: *'YES!'*

Susie: *'I've got learning difficulties and it makes it easier'*

Pete: *'Mine puts a mirror so I can see, and that helps seeing what he is doing.'*

Summary

For people with learning disabilities a 'proper dentist' is one who listens, does not hurt, and who can carry out the majority of required treatment in one place without having to refer the patient on. A 'proper dentist' explains clearly what they are doing in language the individual can understand, talks directly to them involving them in their treatment and not their carer, is unafraid and patient enough to repeat the explanation if there is something the person does not understand, can wait for them to process the information, think and then formulate a reply, does things in stages and explains at each stage what they are doing, and one who uses visual aids or can show treatment stages clearly in the person's mouth.

3.5.3 Appearance

People with learning disabilities were concerned with the appearance of their teeth, from having white to perfectly straight teeth.

FG5 Susie: *'I had to have a brace for a bit because my teeth weren't straight, but that's not as bad as having fillings and crowns and the lot.'*

FG5 Carol: *'That's what they were going to do with my teeth because they were crooked and all that and my teeth have gone cockeyed and they were supposed to be straight but I moved, the brace would have sorted them out.'*

FG5 Mandy: *'My teeth are yellow and I want them to be white.'*

FG5 Mikey: *'What colour should your teeth be?'*

JO: *'It depends on a lot of things like what colour your skin is, bright white teeth are not natural'*

FG5 Steve: *'So what's this on television when they do different projects on toothpaste that are supposed to make your teeth white or squeaky clean and all that lot, what are they talking about, are they talking nonsense or what?'*

FG5 Andy: *'Is it true that it works, is it true that toothpaste makes your teeth white?'*

FG4 Cathy: *'My teeth are brown and I can't do anything to stop what can I do to have white teeth?'*

Interest in tooth colour and appearance made for an animated discussion in two focus groups with arguments about the best toothpaste to use and styles of advertising. This illustrated that people with learning disabilities are consumers of health care products, but interestingly are infrequently seen in advertisements, or regarded as consumers within the general literature.

3.6 Access: Appropriate to need

A service is appropriate to need if a service user is obtaining what he or she requires; whether there is continuity of care and whether the service provided is appropriate to the needs of the service user. Needs of the service user are complex in relation to people with learning difficulties and map onto the wider literature on communication and competence. For example, it is well documented that people with learning difficulties have some form of communication disorder (Beange 1996,

Lennox & Kerr 1997, van der Gaag 1998, Mansell *et al.*, 2002, Bigby 2004). Furthermore, there is evidence to suggest that people with learning disabilities underutilise their communication skills if the context does not provide adequate and appropriate opportunities for communicating (Bradshaw 1998, van der Gaag 1989; 1998). An important aspect of the communication environment is the person or people who know individuals with learning disabilities the best and who can facilitate their communication. This may enable people with learning disabilities to make choices and decisions about their own healthcare and retain some control.

3.6.1 Enabling and disabling support

Support was a theme that constantly recurred, but it became apparent that the type of support was important.

Carer: 'There are very few people that can clean their teeth properly about 90% of people who I work with need support and it can be difficult to get into someone's mouth to clean their teeth if they are not used to it. You try the best you can but we need help. The hygienist years ago was useful because it prepared people for going to the dentist, it was better years ago. With supported living people get less support than when they were living in institutions, now they don't get their appointments as often as they should because the clinics are too busy and there are too many people going there.'

Family member: 'One big issue is that what happens when carers don't have the knowledge or expertise to deal with something like teeth and the person does not have the ability to communicate pain or discomfort? How does the dentist know what to do? How do the carers know when to intervene? Teeth are so important for so many things but they get forgotten amongst other things. Carers need support but they also need to talk to existing family members in case they've missed something but most of the time there is just a void and no communication takes place so issues rumble on. You know it is the vulnerable person that loses out because they have no voice in any of this. We need health advocates who can intervene and mediate.'

Whether it is support by physically accompanying an individual for treatment, support in carrying out oral hygiene, communicating with carers when people live in community homes, or interacting with dental staff there appeared to be a need for health advocacy within dentistry and better educated carers who are more aware of health practices that can enable carers to promote health, and enable people with learning disabilities to become supported in their choices and decisions about their own healthcare. Varying types of support lead to assumptions of competence, namely competence promotion or competence inhibition (Booth and Booth 1994). Competence-promoting

support allows the person with learning disabilities to remain in control, whilst simultaneously developing skills that enable them to cope in similar situations. These could be skills that are simple and taken for granted by the general population, for example making your own dental or doctors' appointment or, alternatively, asking questions concerning your treatment, or describing your symptoms yourself, entering the treatment room alone in private and undertaking any treatment necessary, or developing healthcare behaviours that would aid individual wellbeing.

In contrast, competence-inhibiting support is based on assumptions that the person with learning disabilities is incapable of managing on their own, making decisions and choices, and that intervention is necessary and in their 'best interests'. This second type of support is unresponsive to the needs of people with learning disabilities, is demotivating and crisis-orientated. Furthermore, competence-inhibiting support undermines a person's self-worth and denies any opportunity to overcome problems alone, and make a choice or decision regarding healthcare and lifestyle.

For competence promoting support to be effective the person supporting an individual with learning disabilities needs to possess the requisite knowledge in order to enable the person with learning disabilities to make choices and decisions about their healthcare. The possession of specialist personal and medical knowledge increases in importance, especially in difficult cases where healthcare choices and decisions are vital, and the person assisting needs a thorough personal knowledge of the individual, treatment choices and their outcomes.

Issues appear when individuals lack the verbal and/or communication ability to accurately describe any oral health problems, making them vulnerable and at the mercy of their carers who take on the role of advocate or gatekeeper to optimum oral health. This places dental services in a difficult position because these patients usually are more profoundly impaired and have other health issues that can further impact negatively on their oral health status. Frequently, the only indication of need is when admitted for a general anaesthetic and a thorough oral examination can be carried out and treatment provided where required. However, when the carer lacks oral health knowledge and it remains up to them to discuss treatment options with the person they care for then competence and decision-making cannot be promoted and there is a barrier to care.

3.6.2 Knowledge of dental procedures

Knowledge is involved in communication and competence and this in turn links back as to whether services are appropriate to the needs of people with learning disabilities. Understanding why treatment is necessary and the reasons why some procedures need to be carried out enables people

with learning disabilities to feel involved in choices and decisions about their oral health enabling them to exert some control. Most people knew what a cavity and root canal filling was, many knew about fluoride and what impacted wisdom teeth were, using dental terminology to describe their mouths and illustrating an interest in and awareness of clinical dental procedures. This gives examples of good practice where oral health has been discussed with people with learning disabilities and the examples cited illustrates that they have clearly understood.

There were differing levels of knowledge regarding dental procedures and the reasons why some procedures are carried out.

Rosa: *'I have a number of fillings and some out when I was younger, I also had my wisdom teeth out because they were impacted, you know jammed against the other teeth and pressed against it causing me pain, so they'd never get into my mouth straight and in place. I needed a general anaesthetic for those but for some things I've been sedated. Like chopping the top off a root when the tooth has had root canal done but it's not quite worked. I think sedation is the best option for some situations.'*

Pam: *'I had a bad time with gas, it made me sick and they've stopped doing it now unless people really need it so I just have a needle to make my tooth go numb. I go every six months and they check the fillings in my back teeth to make sure they stay sealed so no bad can start.'*

Sue: *'If I have teeth out on the bottom I have to go to hospital because the main nerve is near the gum and I could end up with a numb mouth if the nerve gets cut.'*

Bill: *'I've got fillings, but not because I eat loads of sugary stuff, it's because I grind my teeth at night and wear them away. I had a cavity that was a root canal because I ground my tooth right down. They didn't know how far down it was and they kept taking a long time, they used rods to clean it out and measured them to make sure they were the right length.'*

Sam: *'I think Sensodyne is good because it stops your teeth from aching, but I think the cavity ones; Macleans, Colgate aren't any good because the adverts say they will stop you from getting cavities and they don't.'*

Steve: *'I've got acid reflux and this makes my teeth sensitive; it makes the tooth enamel weak, so they give me Duraphat to help. I have a pink gel on my gums before fillings and that stops me feeling the needle when it goes in as well.'*

Summary

The role of the carer is extremely important in the life of some people with learning disabilities. The knowledge and understanding that a particular carer may or may not have has a direct impact on how people with learning disabilities are enabled to develop competence and skills in choice and decision-making, and thereby gaining control over their own oral health. There are good examples of explanation about treatment and the need for some procedures, and this also has an impact on how people with learning disabilities make sense of their oral health care. This is an important part of communication. Issues still arise around people with more profound impairments but again carers need to be more aware of the impact of oral health on the body as a whole.

3.7 Conclusion

Issues around access to dental care have been discussed at length for people with learning disabilities (see Owens *et al.*, 2011) and it would appear that for the Sheffield area there are similar issues related to access in its wider conceptualisation. Although for some people access was not problematic, accessibility to the clinics and dental practices were highlighted as barriers because of transport problems, or long journeys that increased anxiety for many individuals, and availability of the type of services that enable choice and inclusion. Not all salaried dental clinics were easy to access because of transport difficulties.

Many people with learning disabilities wanted a general dental practitioner but some perceived their practitioners had converted to private practice or they were unable to afford NHS treatment if they were not exempt from payment.

Accommodation was also an issue within the salaried services; there was difficulty obtaining appointments because of waiting times, and bureaucracy in referral when people moved to different areas leaving little or no continuity of care. Dental services, although under pressure, exhibited many good practices but failed to improve the levels of health literacy for people with learning disabilities who had the ability to take control of their own oral health. Furthermore, there were examples of people with learning disabilities having to take what they were given and being objectified and not treated with dignity or having their wishes respected.

Support for carers and family members appeared to be a necessity, education of carers was needed and many carers felt that they needed support from dental services; the choice of having a domiciliary service where some people could be seen in their own homes with little disruption to

their day would be invaluable for some people. This approach would make services more appropriate to the needs of people with learning disabilities.

People with learning disabilities valued the 'soft' skills of dentists which revolved around interpersonal communication, but they also queried why some dentists appeared deskilled and could not offer a full range of treatment compared to others.

For individuals with more profound impairments issues arose for those lacking the ability to articulate any dental distress. Reliance here is on the carers who can act as gatekeepers or facilitators depending on how well they know the person that they are caring for and the level of their own health literacy.

Dental services used by people with learning disabilities on the whole appear to be under pressure with the numbers of patients that they have, the types of treatment that they can (or cannot) offer, and the lack of seamless care from one system to another. Moving area appears to be a problem for people with learning disabilities because they have little control over where they are housed and services that may have been easy accessible previously suddenly become inaccessible resulting from the move. There needs to be a system in place that enables continuous and seamless access to dental care, which could start with the Learning Disability Partnership Board in collaboration with all service to discuss improving integration and continuity of services.

4.0 Recommendations

Within the Sheffield area it was noted that further support for and education of carers appeared to be a necessity. Enabling carers through training in oral health and encouraging them to understand the importance of oral health within a whole person context should assist competence promoting support and including people with learning disabilities in choices and decisions about their own oral health care. This means developing either a training package, or a series of workshops, perhaps as an addition to the NVQ carer qualifications, with refresher courses occurring regularly. Carers need to be engaged in discussing the differences in oral health status for people with learning disabilities and the issues they may have in enabling oral health care and facilitating choice and decision-making. This may be implemented through the Learning Disability Partnership Board who could facilitate discussion of how best to approach this in Sheffield although such training, education, and support for carers are needed nationally.

Disability awareness training for qualified dentists and dental undergraduates and dental care professionals is needed. There is some evidence to suggest that some dental and dental care professionals are employing a 'deficit approach' to people with learning disabilities and focusing on inabilities rather than abilities which may promote competence. Within the School of Clinical Dentistry in Sheffield there has already been a move towards amending the undergraduate curriculum, and this could be revisited to highlight further areas for improvement. However, this will not reach dental and dental care practitioners who are already qualified and a session on the findings of this project will be included in a training event for dental teams in Sheffield in 2012.

There appears to be a general lack of appropriate local and national oral health and service information available for people with learning disabilities, their carers, and self advocacy groups. Appropriate information needs to be developed that may be adapted over the life course for people with disabilities. The format and content of this information needs to be developed in partnership with people with disabilities, their carers and supporters, and the PCT Dental Public Health Unit (and dental service commissioning team).

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APPENDIX A: Adult Oral Health Questionnaire.

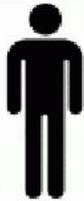


This booklet is to help explain the questions on the 'Adult Oral Health Questionnaire' sheet.

You need to fill in your answers on the other sheet. You might need someone to help you to do this

SECTION 1:

This part asks questions about you



Male



Female

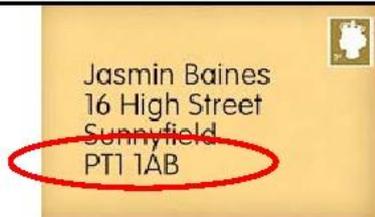
Q1. What is your sex?

This is asking if you are a man or a woman. You need to put a tick in the right box.



Q2. How old are you (in years)?

You need to write your age in the box.



Q3. What is your postcode?

This is the last line of your address. It has numbers and letters. You need to write it in the boxes.

SECTION 2:

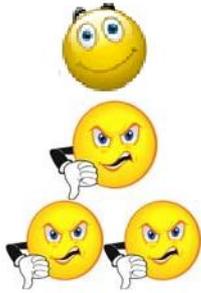
This part asks questions about how healthy your mouth is



Q4: This is about how healthy you think your mouth, lips, jaws and teeth are.

You need to put a tick in the right box:

- Excellent
- Very good
- Good



- Fair
- Poor
- Very poor

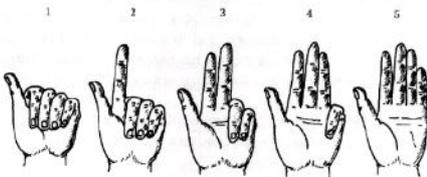


Q5. Have you still got some of your own (natural) teeth?

If some of your teeth are your own (not false), you need to tick the 'yes' box.



If you only have false teeth, you need to tick the 'no' box. You can jump straight to question 7.



Q6. Sometimes teeth fall out, or have to be taken out. How many of your own teeth do you still have?

You need to count how many of your own teeth you have and put a tick in the right box



Q7. Are your top teeth false teeth?

Put a tick in the right box



Q8. Are your bottom teeth false teeth?

Put a tick in the right box



Q9. Have you had pains in your mouth in the last year?

Please tick the right box to say if you have had pains:

- Never
- Hardly ever (maybe 1 or 2 times in a year)
- Occasionally (sometimes)
- Fairly often (quite a lot)
- Often (a lot of times)



Q10. Have you had problems with your teeth or mouth that make it hurt to eat some foods in the last year?

Please tick the right box to say if you it has hurt to eat some foods.



Q11. Have you felt self-conscious or embarrassed because of your teeth, mouth or false teeth in the last year?

Please tick the right box to say if you if you have felt embarrassed.

SECTION 3:

This part asks you questions about visiting the dentist



Q12. This question is about how long ago your last visit to the dentist was.

You need to tick the right box to say how many years ago it was.



Q13. This question is about why you go to the dentist.

- Do you go to have a **regular check up**? - this means you go once every year or two years to have your teeth checked
- Do you go to have an **occasional check up**? - this means you go have gone now and again to get your teeth checked, but not every year.
- Do you only go **when you have trouble** with your teeth? - for example if you have toothache.
- Do you never go to the dentist?



Q14. Is it difficult for you to get appointments to see the dentist for routine care?

This is talking about normal appointments to check your teeth or get fillings. This is not talking about emergency appointments when you have trouble with your teeth.



Q15. This question is about what makes it difficult to get your teeth looked after by a dentist

There are lots of reasons why people find it difficult. Please tick the reasons that are true for you. You can tick more than one answer:



I'm scared of dentists / treatment on my teeth



I don't have time / the surgery isn't open at the right times



I can't get to the dentists



There isn't a dentist near where I live



The dentists are all full and won't take me



The dentists only help people who can pay for it



I can't get into the building where my dentist is



I don't know

?

Something else - there is a box underneath so you can write down any other reasons you have



Q16. Is it difficult for you to get a dentist to look after your teeth when you are having problems?

- If you answer **yes**, go to question 17 next
- If you answer **no**, got to question 19 next
- If you **don't know**, got to question 19 next



Q17. Why do you think it is difficult to get help from a dentist when you are having problems with your teeth?

These are the same reasons in question 15. Use the pictures and explanations for question 15 to help you answer this question.



Q18. Have you had to get help from someone else when you had problems with your teeth? Where did you get help from?

You can tick more than one answer:



No-one



Accident and Emergency



Doctor



Pharmacist



Someone else (please tell us who in the box)

Q19. If you went to the dentist tomorrow, do you think you would need treatment?

Do you think the dentist would have to do anything to look after your teeth or make them better? Please tick the right box to say what you think:



- I would need treatment = Yes, the dentist would have to make them better
- I would not need treatment = No, my teeth are fine
- Don't know

Q20. Is there anything else you want to say?



You can write anything else you want to say about dentists and looking after your teeth in the box.



Q21. This question is asking you about your ethnic group.

Please tick the right box for you.



Thank you for helping us



Please send the questionnaire back in the FREEPOST envelope. It will not cost you anything to post it.



We will not tell anyone what you have said.



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