

Access to dental services for people with learning disabilities: Quality care?

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Abstract

Aims and objectives: To represent the unheard voices of people with learning disabilities and their carers concerning access to dental services. The objective was to explore the oral health experiences of people with learning disabilities and their carers using the social model of disability as a lens through which to view data.

Design: Qualitative methods employed a blend of ethnography and narrative. A purposive sample of ten people with learning disabilities, and their carers, was employed. Interviewing was used as the main tool of data collection, but pluralistic methods were used to obtain and build stories.

Results: The main narratives for all participants centred on issues related to quality care and a wider definition of access than described in the existing dental literature. This highlighted issues related to other dimensions of quality care.

Conclusion: This study suggests that policy and guidance, whilst prescriptive and available, has so far been ineffective in improving access and consequently the quality of oral health care for people with learning disabilities. A modified model of access is suggested for Primary Care Organisations alongside guidance by the British Society for Disability and Oral Health, to inform the commissioning of services that enable optimum access to quality care.

Key words: *Learning disabilities, access, quality care, oral health, policy*

Introduction

It is widely reported that people with learning disabilities are less likely than people without learning disabilities to have their health needs fully met (Whittaker and McIntosh 2000; Powrie 2001; Evenhuis *et al.*, 2001; Hogg *et al.*, 2001; Lennox *et al.*, 2001; Thorpe *et al.*, 2001; World Health Organisation, 2001; Powrie, 2003). Within dentistry, considerable research has been undertaken over the past 25 years on the oral health of people with learning disabilities. For example, although caries rates are comparable, significantly more decay remains untreated in those with learning difficulties (Shaw *et al.*, 1986; Nunn and Murray, 1987; Francis, 1991; Kendall, 1992; Cumella *et al.*, 2001). Improvements in medicine, coupled with dramatic increases in life expectancy for people with learning disabilities, means that new opportunities and challenges have appeared, not only for individuals and their families, but also for the helping professions and healthcare services (Bigby, 2004).

Many of the issues associated with ageing are similar for all groups, but learning disabilities have particular challenges. For example, ensuring that people's voices are heard, and opportunities for choice, decision-making and inclusion are maximised whilst simultaneously providing support to

enable people with learning disabilities to achieve quality of life. Moreover, research in dentistry suggests that ageing appears to increase susceptibility to reduced levels of oral health (Turner *et al.*, 2008), and in a group where need has still not been fully met there are even greater implications related to quality of life.

Since the publication of *Valuing People in England* (Department of Health, 2001) and *Valuing People's Oral Health* (Department of Health, 2007a) the drive has been to improve healthcare for people with learning disabilities; the implications of policy and statutory responsibilities of medical professionals are undergoing change. Consequently, there are greater opportunities for user involvement in the planning and delivery of services and the forces that are shaping these changes are unlikely to go away. Although there have been improvements, recent studies imply that barriers to dental care still exist (Cumella *et al.*, 2001; Hallberg and Klingberg 2004; Hallberg *et al.*, 2007; Scully *et al.*, 2007; Davies *et al.*, 2008).

If we use the categories of barriers suggested by Scully *et al.* (2007, p1977) in relation to oral healthcare for people with learning disabilities, we can structure the literature accordingly.

- Barriers with reference to the individual
Lack of perceived need and lower priority given to oral healthcare (Hallberg and Klingberg, 2004); difficulty complying with instructions/inability to carry out oral health self care (Bollard, 2002); anxiety or fear lead to management difficulties, sometimes emanating from traumatic experiences (Hennequin *et al.*, 2000; Emerson, 2001); remaining still for treatment (Russell, 1992); lack of awareness of carers regarding oral healthcare and low expectations (Cumella *et al.*, 2001); and access problems including transportation to/from and within the surgery (O'Donnell, 1985).
- Barriers with reference to the dental profession
High staff turnover, resulting in a lack of continuity and reduced levels of trust and co-operation because a relationship is not being built with the patient (Pratelli, 1998); inequitable distribution, training inappropriate to changing needs and demands (Gallagher and Fiske, 2007); insufficient sensitivity to patient needs and demands, lack of information received about treatment (Hallberg *et al.*, *ibid.*); lack of knowledge, funding, and constrained physical environments (Edwards and Merry, 2002; Hallberg *et al.*, 2007); lack of accessible language and poor communication skills on the part of the healthcare team as a contributory factor to health inequalities (Sentell, 2007).
- Barriers with reference to society
Insufficient public awareness and positive attitudes to oral health promotion, inadequate oral healthcare facilities and manpower planning, insufficient support for research (Scully *et al.*, 2007; Rouleau *et al.*, 2009).
- Barriers with reference to government
Lack of ability to match policy with practice, inadequate resourcing for oral care services (Dougall and Fiske, 2008); low priority placed on dentistry within the NHS leading to privatisation (Rawlinson, 2001).

Whilst there is little argument that barriers exist, the literature displays a tendency to represent people with learning difficulties as a problem and pay less attention to adjusting their environment to reduce the barriers that they encounter. Suggestions for reducing barriers have included measures such as discretionary payments for non-salaried dentists to allow for the extra time required (Davies *et al.*, 1988; Nunn and Murray, 1988; Hallberg *et al.*, 2004). Arguably, this is a move towards increasing choice and availability of oral health care for people with learning disabilities but does not fully address the barriers faced by them in relation to their oral healthcare.

Current policy guidance within the UK advocates a social model of disability approach where disability is envisaged as a barrier constructed by society, or all the things that im-

pose restrictions on disabled people. This ranges from prejudice, institutional discrimination, inaccessible buildings, transport systems, segregated education, and exclusion from the workplace and healthcare systems (Oliver, 1990, 1996; Barnes, 1991). Adopting a social model approach to people with learning disabilities does not deny the problem of disability but instead locates it firmly within society (Oliver, 1996). Therefore the limitations of the individual are not the issue, rather it is society's failure to provide appropriate services that adequately ensure the needs of disabled people (Oliver, 1990, 1996). The social model argues that medical personnel have a role to play in the lives of people with disabilities but suggests that problems arise when medical personnel use their knowledge and skills to treat disability rather than illness. So for example, deciding what kind of medical services people should receive, what kind of school they should go to, indeed anything that divides the lives of people with disabilities to suit professional activity can be claimed to be disabling because it excludes the voices and the people it claims to represent. Furthermore, pictorial representations of disability have a tendency to reinforce the image of physical limitations, which is echoed in how practices are reviewed for being disability compliant because there is a tendency to focus on physical impairments which can be measured rather than cognitive, which are far more difficult to ascertain. Looking at access through the lens of the social model of disability gives us a very different perspective which will now be reviewed briefly.

Access to dental services appears to be concerned mostly with people with physical disabilities. For Dougall and Fiske (2008), access to dental care for people with disabilities comprises four key areas:

- Access to the building
- Access to the dental surgery
- Access to the dental chair
- Access to the mouth.

However, this returns to a medicalised vision of people with disabilities and excludes people with learning disabilities because it views access in terms of physical limitations and the environment. Various authors have sought to challenge this perception because for people with learning disabilities, access is multi-dimensional and comprises of more than just physical access (Shakespeare, 2006; Thomas, 2007). This is further acknowledged in the Commissioning Tool for Special Care Dentistry (British Society for Disability and Oral Health, 2007).

When *Valuing Better Oral Health* (Department of Health, 2007a) was published it implied that there were oral health inequalities for people with learning disabilities, but did not describe their determinants, and more crucially, did not include user voices. The importance of promoting inclusion and working in collaboration with service users to strengthen accountability is echoed in section 11 of the Health and

Social Care Act in England (Department of Health, 2003). This need to take steps to include people with learning disabilities in choice and decision making about their health care is re-emphasised by Grant and Ramcharan in *Valuing People and Research: The Learning Disability Research Initiative* (Department of Health, 2007b). Unless there is active listening to the views and wishes of people with learning disabilities then they cannot be involved in healthcare choice and decision-making processes, or service delivery and crucially, their experiences of access to services which transforms them into active citizens rather than passive receivers of care.

Methodologies employed for assessing oral health with people with learning disabilities often rely on quantitative measures. For example, the pilot study of Davies *et al.* (2008), using a cross sectional design, identified that there were unaddressed needs but added little to existing knowledge of the barriers that people with learning disabilities may face.

The paucity of the subjective views of people promoted this research, which aims to represent the unheard voices of people with learning disabilities, their carers, and their experiences of access to oral health care.

Methods

Qualitative research is the most appropriate form of research to adequately explore subjective experiences of people. The methodological basis for this research originates from the fields of phenomenology, social constructionism, symbolic interactionism, and ethnographic perspectives, providing the framework for thinking about people's experiences in multiple but related ways. The methodological approach in this study uses a blend of ethnography and narrative.

Ethnography is derived from the field of anthropology and could be explained as description and interpretation of the cultural beliefs, values, and social structure of a group through fieldwork (Robson, 2002; Hammersley and Atkinson, 2007). The researcher endeavours to seek acceptance and become a part of this group (Taylor and Bogdan, 1998). This becomes more evident when writing up the study as the researcher becomes part of the process (Geertz, 1973). There are many different 'tools' that may be employed with this methodology; for example direct first-hand observation and in-depth interviewing. Above all, it relies on a highly reflexive stance by the interviewer, who takes a step back and examines their own views and beliefs in relation to the research and how these views and beliefs may drive and affect the process (Taylor and Bogdan, 1998; Hammersley and Atkinson, 2007). Using interviewing and field notes, to gain people's perspectives, enables the interviewer to gain an understanding of the lifeworld (the world that is lived in before analysis and reflective representation).

Narrative helps the interviewer unpick the layers of subjective meanings within the stories told (Plummer, 2001). In

essence, alongside field notes, narrative allows context to be given to a situation, which may be fraught with confusions and ambiguities of a solely transcribed text. Narrative is becoming increasingly accepted within the field of Medicine (Holloway, 2005) and the contribution of human experience is providing an important dimension in knowing, and addressing the uniqueness of the person. Additionally, the use of narrative to contextualise experiences of medical illness has been employed by Bury (2001).

Narrative analysis is flexible, it may be case-centred and generates 'categories', and moves beyond the surface of the text towards a broader commentary, unpicking the many layers of human thought, expression and imagination (Reissman, 2008). It identifies how knowledge is constructed in the everyday world through the communicative act of storytelling. Analysis is further informed by ethnographic observational notes taken during interviews. Quality indicators of reliability and validity are not approached in the same way as quantitative research but instead viewed in terms of veracity, genuineness, trustworthiness, and dependability (Lincoln and Guba 1985, 1986; Hammersley and Atkinson, 2007).

To address quality, and notions of trustworthiness, the emergent data were triangulated against each other, with the researcher's observations and with existing published peer reviewed research. Member checking also occurred in that the researcher returned to the participants with the stories to check that they agreed with his interpretations.

The data for this paper came from an elective project of an undergraduate student who worked voluntarily in his spare time (and had done so for five years, and prior to him becoming a dental student) with a charitable organisation who provided specialist projects for people with a range of learning and physical disabilities, supporting them to participate in leisure activities. Activities typically ranged from youth-centre-based arts and drama workshops, to day trips to theme parks and museums, and aimed to provide an enjoyable day for people with learning disabilities, and respite for carers. The spectrum of people that attended ranged from mild/moderate to severe learning difficulties: moderate for example, being those who may only need slight support in communication and being able to get around; to severe, where even basic tasks such as eating and toileting must be supported. The student was used to communicating in different ways with those that he worked with and unknowingly used the social model of disability (Oliver, 1990, 1996) within his work because he explored ways of enabling individuals by learning their methods of communication and seeking to reduce the everyday barriers they faced in their lives. This is in contrast to problematising them and viewing impairment as a cause of disability. Support, instruction, and guidance were given by an experienced qualitative researcher in the field of disability regarding interviewing people with learning disabilities and narrative analysis of emergent data.

Sample

A purposive sample of ten people with learning disabilities and their carers who self selected was chosen to explore experiences of dental services. This differs from convenience (accident/opportunity) sampling because this type of sampling chooses the nearest informants, regardless of typicality, until the required sample size is reached (Cohen *et al.*, 2000). Using narrative means that issues related to data saturation (which is derived from grounded theory) do not apply because it is intended that full and rich personal accounts are obtained from the sample used and commonalities are explored across the sample (Hale *et al.*, 2008). In purposive sampling, the researcher handpicks the individuals to be included in terms of how typical they are for the specific needs of the study. As the name suggests, the sample is chosen for a specific purpose; had they had contact with dental services and did they have learning disabilities? The sample does not pretend to represent the wider population. The age range of people with learning disabilities was 19-55. The people lived independently in the community with support in a mixed socio-economic area which for the purposes of this study has been named Berryworth.

For the sake of definition we have used IQ levels of 50-69 to denote mild learning disability, IQ of 35-49 for moderate, 20- 34 for severe and <20 for profound learning disabilities (World Health Organisation, 1996; Mackenzie 2005), although this does not always mean that there is clarity because of the limitations of IQ testing used to define learning disability. It is thus a mere guide to illustrate the degree of cognitive impairment.

To protect participants all names, places and identifiers have been altered. The study was undertaken outside the Yorkshire and Humber region and participants utilised a mix of dental services.

Ethics

Ethical approval was obtained from the University of Sheffield Research Ethics Committee (UREC). The director of the organisation gave her permission for people to be approached, and advised on the individuals whom she felt would feel happiest being contacted. A letter was prepared with input from the organisation and people with learning disabilities as to its readability, and sent to a sample of twenty people and their carers. Ten replied. A follow up phone call was then made to arrange an interview time.

Interviewing

A prepared, easy-read sheet was used to assist in explaining the study and the process of continuous consent was used throughout the interview. It was stressed that a false identity would be provided and that individuals had the option to terminate the interview at anytime. To protect participants, the residential location of individuals was also altered. Permission was also asked to record the interviews under the condition that the tape would be destroyed after listening

and data transcription. A recorded interview was carried out with each service user and carer. The questions were open wherever possible, and the researcher had a Memory Aid (Kvale, 1996) to guide the direction of the interview.

Various authors (Taylor and Bogdan, 1998; Hammersley and Atkinson, 2007; Owens and Saeed, 2008) have explained and demonstrated the need and importance of taking 'field notes' throughout the interview to provide context. Using this guidance, the researcher described the setting, emergent feelings, anything unusual that happened during the interview, and any other interactions that were non-verbal. Any other change that happened subsequent to the interviews was also recorded in note form.

In cases where individuals struggled to communicate, narrative methods were employed (Booth and Booth, 1996: see Owens, 2007 for further discussion) to enable participants to communicate, and to gain their stories. For example, Michael used PECs Boards (Pyramid Educational Consultants; www.pecs.org.uk), where individuals observe a series of standardised images or pictures to aid their understanding of forthcoming and current activities/events. The boards were used to enable them to convey their thoughts. People who knew individuals the best also assisted in enabling stories to be formed. A narrative was then built from the interactions. Further training in the use of Makaton was also undertaken (www.makaton.org).

Reflexivity

Reflexivity is important in qualitative research because it exposes values and beliefs of the researcher (Atkinson and Hammersley, 1994). The researcher's interest in this field stems from long term voluntary working with an organisation that aims to support and enable people with learning disabilities to access pursuits that will add significantly to their quality of life. The researcher was interested in whether healthcare matched these aims of accessibility and enablement. Not having any first-hand experience of healthcare within the context of Special Care Dentistry meant that the researcher had a relatively open mind. Disclosure of the researcher's dental background may have caused participants to change their stories, coupled with this is the power differential that exists between both the researcher and participant. Although the aim was to reduce this differential, the researcher was aware that this may not be possible. For example, prior knowledge of the fact that the researcher was a dental student may have made the participants reluctant to disclose negative experiences.

Analysing the data

An inductive analysis was used where interviews were read and reread to identify emergent themes (Silverman, 2006). However, narrative analysis refers to a family of methods for interpreting texts that have in common a storied form and is also a way of conducting case centred research (Riessman, 2008). Within narrative research, both the inter-

view and transcription becomes part of analysis because interpretation begins in the field and continues throughout the whole process, blurring the boundaries between interview, transcription and analysis. Individual cases are read as extended accounts and can be combined with category-centred models of research such as grounded theory, inductive thematic coding, and ethnography, allowing for close analysis of the cases. Although case-centred, the analysis does generate ‘categories’, or general concepts, and moves beyond the surface of the text towards a broader commentary (Riessman, 2008). The cases were interpreted as a whole but each case contained marked similarities related to access and quality care. In this study, prior theory served as a resource for interpretation and the researcher then moved between prior theory and the spoken narratives throughout the process of analysis. This is termed narrative shaping and entails imposing a meaningful pattern onto stories that would otherwise appear to be disconnected (Salmon, 2008). Narrative analysis differs considerably from a qualitative approach that cuts data into discrete units of analysis. One example is framework analysis where a clearly defined procedure allows policymakers access to an iterative process and facilitates researchers in meeting tight deadlines (Bowling and Ebrahim, 2005).

Results and discussion

When analysed, the main narratives for all participants centred on issues related to quality care and a wider definition of access than described in the existing dental literature (Dougall and Fiske, 2008).

Choice and access

All service users and families interviewed had a named dentist they attended regularly. Therefore, all were aware of the availability of general dental services.

Chris and Emily’s mother, Susan, spoke to several dentists in the area before registering to gauge opinion upon how each would seek to treat her children’s teeth. This was because she was also aware of the availability of orthodontic services in the area, and understood that the general dental practitioner (GDP) would be the gatekeeper to this.

Michael’s mother would have liked to have taken him to another dental practice a bit further away because she has heard that they “go that extra mile” when treating people with special needs. However, support services did not have the capacity to support her choice. In this situation support services were acting as a barrier to Michael and his mother because they reduced his access. Recently NHS policy has emphasised providing ‘choices’ for patients:

“The introduction of free choice means that patients re-

ferred to see a specialist can choose where they will be treated [...].” (National Health Service, 2009)

Michael and his mother simply do not have the choice of services available to allow him to see those that would facilitate his treatment.

Physical access to services

If one considers physical access in terms of actually transporting oneself from a place of residence to that of the dental service; a variety of responses was encountered. Two people walked to their dentist, such was the close proximity and convenience. However, even when services are convenient there are other barriers that people with learning difficulties can encounter. For example Rachel said that she would also walk, but was afraid of crossing a main road nearby so this presented a barrier to her. She told the interviewer that she overcame this by taking the bus instead. Everyone else required transport to get them to their appointments. However, this was easier for some than others. Paul and the individuals in the residential scheme said that they had round-the-clock carers, all of whom had cars, so transportation was never a problem. In contrast, Michael required two-to-one supervision because of his tendency to run off and explore which was linked to long periods of confinement indoors. This, and his mother’s inability to drive, meant that there was a procedural barrier to accessing appointments.

Sarah attended a local general dentist whose surgery was on the top floor. She commented that “*the steps are quite deep I have to watch*”, she felt unsteady on her feet and would feel safer if there was a lift or stair lift. In comparison, the users of the Salaried Dental Service (SDS) made no comments about physical access problems because ramps and wheelchair access were in place. Under the Disability Discrimination Act (2005), it is required that businesses make ‘reasonable adjustments’ to their premises to make them more accessible. However, the emphasis here is on interpretation of the phrase and for some premises it may be that it is not reasonable to adjust them.

Adaptability of services to needs

Important issues relating to the adaptability of services, for people with learning disabilities in particular, focus on whether they are available at the right time, fit personal and family schedules, and are dependable. All except one of the service users had a sufficient level of verbal articulacy to be able to effectively communicate any sensations of tooth pain to their carers, and to dental professionals. Sarah, for example, said that when she had toothache, her mother “*rang up an appointment for me to go and have it looked at*”.

However, accessing a dentist when in pain can be difficult when lacking verbal articulacy. Michael, for exam-

ple, relied on his main carer (his mother) to pick up on his cues. The carer is usually the person that knows the individual best and often interprets changes of behaviour with greater accuracy because they are with that individual every day. Michael's mother mentioned that he had started chewing his toothbrush one side of his mouth, and was uncertain whether this was an indicator of pain, but had not arranged an appointment with the dentist to avoid appearing foolish.

In this situation, the carer acts as gatekeeper to care, and so may facilitate or prevent access, depending upon the speed at which they act. Moreover, if dental services had built trust and emphasised that they valued Michael's mother's knowledge of him, contacting the services would not have been an issue for her. In addition, Michael's mother had difficulty explaining the need to visit the dentist, something as simple as communicating using photographs of the dental surgery and staff would have helped considerably in explaining where they were going and why. His mother reported that nobody had taken the trouble to find out how Michael best communicated. This is in marked contrast to the aims of Special Care Dentistry (SCD) and guidance within their commissioning tool "[...] Care should be provided by the right person, in the right environment [...]" (British Society for Disability and Oral Health 2007, p. 19). Plus two of the four key aims that SCD aims to provide:

1. A patient centred service, which aims to provide and maintain optimum oral health.
2. Integrated front line care, which is organised around the needs of the vulnerable adult, rather than professional boundaries.

(British Society for Disability and Oral Health, 2007).

A common feature for individuals with autistic spectrum disorders is the need for routine and regularity. This need crept into conversations with individuals:

Chris: *"I prefer to see the dentist in the afternoon... never in the morning"*.

Chris told the interviewer this because it would often trouble him to break his routine for an appointment. His mother clarified, stating that she had *"real battles"* if they said it was a morning appointment. Being available at the right time again rests on getting to know the service user as an individual and taking into account their needs, and those of the carer who has to organise and take them to appointments. There may even be a justification here for making appointments for Chris at regular intervals and building oral hygiene into daily care regimes.

Another issue is that of medical forms. It appeared that one SDS clinic required that a lengthy medical history form be completed at most, if not every appointment.

Whilst medical history taking and updating is important and families who complained about this acknowledged that services may be seeing medically challenging individuals, they felt it unnecessary to do this every time. The issue is here is how medical histories are updated. For example, an easy read sheet using Photo Symbols 3[®] (<http://www.photosymbols.com/>) could have been sent to Rachel prior to her appointment, she could have discussed this with her mother, and then indicated any changes in her medication at her appointment without the need for a lengthy questionnaire. This would have been more line with the changes in the Mental Capacity Act (2007) on guidance on involving people in their healthcare and enabling Rachel to be an active participant by presuming she has the capacity to inform.

Attitudes of dental professionals

Susan sought access to orthodontic services, but was concerned by the attitude of GDPs towards her children: Susan: *"[...]but he wouldn't advise treatment for the thing that I wanted- and his teeth were quite crowded and sticking out a bit...but not everybody would see it important to refer them on- that's the issue that's more at stake[...]"*

Rhia's mother encountered similar attitudes:

Researcher: *"Why wouldn't the dentist see Rhia?"*

Mother: *"Erm...because with Rhia having Down syndrome, he didn't think it was worth bothering with... You get quite a lot of prejudice, more than you realise, when you get someone in the family with disability."*

Chris, Emily and Rhia all had learning difficulties and Down syndrome; dental services excluded them because of the way their needs were defined in terms of their disability. They became objects and part of a group, not individuals in their own right; therefore they were ineligible for services.

Attitudes towards people with learning disabilities were frequently mentioned, and whilst discrimination is present within society, professionalism within the dental services coupled with guidance by SCD should, in theory, counter discrimination. The metaphor of being 'brushed off' by dental services appeared in two interviews, alluding to people with learning difficulties not being considered worthwhile and taken seriously. This is reflected by work before (Flynn, 2002; Lindsey, 2002) and after the 'Death by Indifference' report (Mencap, 2007; Gibbs *et al.*, 2008) and links back to quality of life and the social acceptability of services by service users because valuing people with learning disabilities means listening to them, treating them with dignity, and crucially, involving them in person-centred planning about their oral healthcare

needs, as per guidance in the commissioning tool (British Society for Disability and Oral Health, 2007).

Continuity of care

A service can only be deemed accessible if it is appropriate to one's requirements of that service. Continuity is an issue that arose and was of importance to many service users. Valuing People's Oral Health (Department of Health, 2007a) asserts that it is important to build a relationship with the patient (and carers in this case). Sarah's mother, Julie commented that constant changes have been hard for them:

Julie: *"I think it's been... generally, it's been quite difficult because they've had so many changes. We used to have Mr M, and he was very good, and then we had him for years and years and years, and then we had a Mr H, which was good. But since this lady dentist has taken over, we've had a lot of dentists coming, you know what I mean?"*

Using Makaton, Sarah said that she was nervous with people who she did not know and that strange faces upset her; she said it made her frightened. Acclimatising to new faces at every appointment did little to ease her anxiety; this then had repercussions in terms of management if she required treatment.

The problem of lack of continuity was also faced by Chris and Emily whilst being seen by the orthodontists at the hospital:

Susan: *"And people kept changing too, so that was difficult... the staff. They leave and then they don't replace them for a while."*

In these long-term challenging cases like those of Sarah, Chris and Emily, continuity of staff and seeing familiar faces may actually assist in the treatment pathway. Continuity of care means that changes in advice and treatment plans proposed by different medical professionals are avoided, and a relationship of trust and co-operation is built between patients, their families and carers and staff. This is stated implicitly in the guidance on integrated care pathways (British Society for Disability and Oral Health, 2001).

David gave an example where distrust and bad experiences of dental professionals have been eased by consistently seeing a dentist whom he likes and trusts:

David: *"Still hurts then moved onto Martin. That dentist on Cathole Lane, Gregory. He left there now, somebody else took over. Never go back there again. Sticking with Martin."*

For these patients, a Health Action Plan (HAP) (Department of Health, 2001) may help dentists and other health-care workers to collaboratively deliver services that are appropriate to the service user's needs, and enable continuity of care. However, blank expressions were communicated when questions were asked about the HAP. Nobody had ever heard of them. Michael's mother thought she had received one, and gave it to the researcher to look at, on closer inspection it was actually a Nurses' Assessment. Interestingly, there was no reference to Michael's oral health needs in the document. In not placing oral health needs as a priority, general health services and dental services had not collaborated with one another. As a result, Michael was not desensitised to the dentist at an early age, making his future care more challenging.

The HAP would also contain information about medicines that the person is taking. For example, Sarah was taking anti-epileptic medication in a sugar-syrup form before bed. Her GDP had advised her to brush after taking her medication. Having a HAP would have highlighted her high caries risk, making it known to her GP, who could then have prescribed a sugar-free medication.

Financial costs

All of the service users interviewed qualified for free NHS treatment, and all except Rhia had taken this up.

Rhia's Mother: *"It's private now, it was NHS but then they had the big change over...she's just too good to, to find an NHS dentist, finding another one like her...don't want the pain...it is a bit of a risk"*

Although Rhia's mother perceived the dental care her family received was worth paying for, it is unfortunate that she lacked the confidence to seek more affordable and accessible services due to bad experiences, mostly centred on attitudes of dental professionals. Rhia's mum felt that previously her daughter had been devalued and uninvolved in treatment choice and decision-making because she had learning difficulties. Using Makaton to tell me about her trips to the dentist Rhia said that she liked her dentist, she was good and made her feel safe and she did not want to see anyone else.

Commentary

To the authors' knowledge, this is the first study to explore the views and experiences of people with learning disabilities of their dental care. The recent Steele Report (2009) indicates that access to care is a problem and recommends that dental contracts are developed: *'[...] with much clearer incentives for improving health, improving access and improving quality.'* (p.7).

This study reveals that access to oral healthcare for people with learning disabilities varied greatly. In some instances, attitudes revolved around a medical model of care where people are seen as objects, rather than individuals. This devalues and excludes people with learning disabilities from their healthcare decision-making process. Policy guidance for the implementation of a Health Action Plan (HAP) for each person with learning disabilities by 2005 as mentioned in *Valuing People* has not been successfully realised. This is similar to individual programme planning (IPP) which only reached a minority of service users and then was replaced by person-centred planning (PCP) without addressing the barriers to implementation (Mansell and Beadle-Brown, 2004).

In some cases there was a lack of collaboration and partnership working between healthcare and social services and the individual and/or their carer. This view has been previously highlighted (Lindsey, 2002). One of the requirements for effective partnership working is mutual trust which becomes of pivotal importance when working with patients (Fugelli, 2001). Continuity of care is one factor involved in building mutual trust and making services more appropriate to need and there was evidence to suggest that this was happening in some cases, but not all. Dental services were still not being included as part of the health planning team and the increase in life expectancy, coupled with more people with learning disabilities living independently in the community means that there are higher demands on dental services to support them. People with learning disabilities should have the right to choose where they want to receive dental care and have their needs and opinions regarding their oral health care respected. Part of facilitating choice for people with learning disabilities rests with Primary Care Organisations (PCOs) to arrange a greater level of access to dental services.

In 2003, the Health and Social Care Act required NHS providers and local authorities to work together to bring about improvements in healthcare (Department of Health, 2004). *Valuing People* (Department of Health, 2001b) emphasised working in partnership to bring about positive change for people with learning disabilities. It also emphasised standards and equity of services which would lead to quality standards criteria. The specialty of Special Care Dentistry (SCD) has defined those quality criteria standards in greater detail (see British Society for Disability and Oral Health, 2007, pp.17-18). Various authors (Maxwell, 1984; Donabedian, 2003; Styring and Grant, 2005) have outlined different dimensions of quality healthcare. Within this study, one dimension consistently identified was access.

However, as can be seen, access is far more complex than physical access and for Penchansky and Thomas (1981), the five dimensions of access comprise; availability, accessibility, accommodation, acceptability, and

affordability. The authors of this paper are aware that there is a large body of literature on the complex and multi-layered nature of access to healthcare (Aday and Andersen, 1974, 1975, 1981; Andersen et al., 1983; Andersen et al., 2007). The aim has not been to define access and for the objectives of this paper the concept of access is more practical and defined in terms of the degree of 'fit' between people with learning disabilities and the healthcare system in relation to dentistry, thereby providing a more practical application for commissioning services. Therefore, blending the work of Maxwell (1984) with Penchansky and Thomas's (1981) structural definition of this concept has added a sixth dimension and produced a modified version which can then be used to look at the data again. *Figure 1* shows a modified model of access.

In summary, access may be defined as having six dimensions which are non-discrete and may overlap:

- Availability: the volume and type of services in the area that enable choice and inclusion
- Accessibility: the physical means by which the client reaches services (this can be both inter and intra building and may also mean distance travelled, and/or barriers to travel experienced), and the proportion of primary care services accepting people with learning disabilities
- Accommodation: How easy it is for the client to get 'through the door' (for example opening times, flexibility and waiting times when making appointments, ease of transit through bureaucracy; i.e. forms/procedures), getting to know the patient as an individual who has unique needs, and whether there is a gate-keeper to access
- Acceptability: the level of satisfaction expressed by the client
- Appropriate to need: is the service user obtaining what he/she requires from the profession, continuity of care and whether the service provided is appropriate to the needs of the service user
- Affordability: The costs of the service, and ability to pay for it.

Conclusion

Under all six dimensions of access there was evidence of good practice. However there was also evidence of barriers to access. For example, some professional attitudes reflecting the medical model of care saw individuals as objects and failed to acknowledge that people with learning difficulties have the same rights to dental treatment as others. Using the social model of disability as a lens through which to view the data highlights these issues.

This research suggests that whilst policy and guidance is prescriptive and available, awareness amongst dental and allied health professions can be low. Consequently care received by people with learning disabilities may

Figure 1.



be less than adequate. It appears there may be minimal information-sharing between various areas of health and social care, partially due to the lack of provision or implementation of Health Action Plans (HAPs), and the lack of collaboration and co-operation within and between services. One suggestion is that the Department of Health should consider an alternative strategy to the HAP, or devote more resources to development and implementation in consultation with professional bodies. Primary Care Organisations (PCOs) could use the modified model of access and employ the guidance by the British Society for Disability and Oral Health (2007), in commissioning services to ensure all areas of access are optimised for each practice, thereby enabling an increase in quality care.

This is a small scale study giving only a snapshot in a limited area and one further suggestion is that more inclusive research should occur nationally to explore the oral health experiences of people with learning disabilities in order to gain a fuller picture.

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