

Adults with learning disabilities experiences of using community dental services:

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Perspectives of Community Dental Services

Title - Adults with Learning Disabilities experiences of using Community Dental Services: Service User and Carer Perspectives

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Accessible Summary

- The government and other organisations say that improving health care is important for people with learning disabilities
- We asked people with learning disabilities and the people who look after them what it was like for them when they went to the dentist
- Those we asked said that when they went to the dentist they knew that those they saw knew about looking after their teeth
- Some of those we talked to though said that certain things needed to be better

Abstract

The government alongside other health and social care organisation have identified the need to improve the care provided for people with learning disabilities. This service evaluation aimed to explore the experiences of people with learning disabilities and their carers who accessed community dental services. Adults with learning disabilities (n=4) and their carers (n=6) took part in one to one, face to face semi structured interviews. Generally, participants were satisfied with community dental services and in particular valued the skills and the competence of practitioners. However, when dissatisfaction was expressed this was generally as a result of poor communication and the transition from child to adult dental services. Conclusions are discussed and recommendations are identified.

Key words – adults with learning disabilities, carers, community, dental services, service evaluation

Introduction

The Government together with organisations across the health and social care system has pledged to transform health care for people with learning disabilities (Department of Health, 2015). Those with learning disabilities have more health problems than the general population and die at an earlier age (Emerson et al, 2011).

Providing good dental care is essential in promoting the general health and quality of life for people with learning disabilities (Daly et al, 2013). Whilst it is recognised that they should have equal access to oral healthcare services and equitable oral health outcomes, this is not always the case (Dougall & Fiske, 2008). A study by Baird *et al.*, (2008) investigated the availability of facilities, including parking, accessibility and toilet amenities, as reported by general dental practitioners and views of practitioners in relation to provision of treatment. Findings indicated that up to 77% of the 120 dental practices who responded were considered by practitioners to be accessible to someone using a wheelchair but that only 7% also had suitable parking and toilet facilities. The majority of respondents treated patients with a physical disability and 76% of practitioners reported that they found it difficult to provide treatment to this group.

In conclusion, findings from the evaluations and studies discussed have highlighted the important issues in respect of dental care for people with learning disabilities and support the need to evaluate existing services in the UK. The literature reviewed indicates the majority of approaches to evaluating dental services are quantitative using validated questionnaires. This does not fulfil the aim of this service evaluation for gaining meaningful feedback from the patients and their carers. This service evaluation

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conducted face to interviews with patients and their carers in order to explore their experiences of and expectations of community dental services and the impact of these services on their health and wellbeing. Findings were then used to inform community dental services practices and the future development of a questionnaire which could be disseminated to a wider audience.

1. Objectives

The objectives of the service evaluation were:

1. to explore patients and their carer's expectations of community dental services
2. to map out the main processes that patients and their carers experience during dental health treatment
3. to identify patient's and carer's perceptions of the strengths and limitations of the service
4. to explore patient's and carer's perceptions of the impact of the service on their health and well being

Methods

Design: A qualitative approach, using a purposive sampling strategy was initially adopted to explore service users' and their carer's experiences and perceptions of community dental services. However, due to a limited response from participants an opportunistic sampling strategy was subsequently implemented.

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The evaluation involved semi structured, face to face interviews with 4 patients with learning disabilities and 6 carers. All of the patients accessed dental services in a large community NHS Trust in the North West of England. The carers all had the responsibility for looking after an adult with learning disabilities.

Procedure: Dental staff at two sites across the Trust, approached patients and their carers during a routine dental visit to facilitate recruitment. Recruiting from two dental clinics was aimed at promoting a maximum variation sample. Recruitment was based on their knowledge of the patient's medical history and the inclusion criteria for the study (Table 1). The dental staff approached attending patients and their carers to explain about the evaluation and to identify whether they were interested in participating in an interview. After a verbal expression of interest, the patient's or carer's contact details were given to the researcher within the community Trust who then sent out a participant information letter in the post together with a consent form, a response sheet and a free post envelope. Interested participants then returned their response sheet and they were then contacted by telephone to arrange a convenient time and venue when the interview could take place.

Table 1. Eligibility Criteria

	SERVICE USER	CARER
Inclusion Criteria	Patients selected to take part must:	Carers selected to take part must:

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	Have a recognized learning disability	Be a carer, relative or significant other of an adults who has learning disabilities who has used community dental services on at least 1 occasion
	Have used the community dental service once during the previous 12 months	Have accompanied the patient to a dental appointment on at least one occasion during the previous 12 months
	Have the capacity to consent	Have the capacity to consent
	Be 18 or over	Be 18 or over
Exclusion Criteria	Patients selected to take part must not:	Carers selected to take part must not:
	Have a serious mental health illness	Have a serious mental health illness

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Overall, 10 people participated in the interviews consisting of 2 males and 8 females. Of these, 4 were patients and 6 were carers. Four carers were parents and the remainder support workers. Only 1 patient was interviewed alone and 4 carers were interviewed alone. 2 of the interviews were conducted as a dyads, the first consisting of the patient and 1 carer and the second the patient and 2 carers. For the purpose of reporting the findings and to protect anonymity participants have been given pseudonyms and extracts have been labeled P for patient and C for carer.

Prior to the interview informed consent was obtained from the participant. Assurance about confidentiality and anonymity were reinforced to participants during the consent process. For the semi structured, face to face interviews a framework was used which included the following topics:

- communication
- contact with dental community dental services
- arranging appointments including routine and emergencies
- the physical environment including privacy and dignity
- dental staff and their attitude
- the dental consultation and treatment
- outcomes following treatment including oral health and self care

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The interviews lasting between 18 and 60 minutes were audio taped, except for one with a carer who expressed a wish that the interview was not recorded but they allowed notes to be taken. All recorded interviews were transcribed verbatim. Thematic analysis was initially adopted to identify key issues involving systematic identification, charting and sorting of the data (Miles & Huberman, 1994). Analysis was iterative, with some broad themes identified which were then broken down into subthemes (Glaser & Strauss, 1968). What followed included the comparing of data between individual transcripts. Regular meetings between the researchers throughout the evaluation project allowed for the further reduction of themes and the development of categories.

Results: Initially, subthemes were identified and these were then reduced into three themes, each containing a number of sub themes.

Table 2: Themes and sub-themes identified in the data

THEME	SUB THEME
1. COMMUNICATION	Establishing Relationships
	Specialist Knowledge (including transition)
2. EXPERIENCES	Anxiety and Frustration
	Attitude and Dignity
	Self care - Prevention
3. ENVIRONMENT	Access

	Safety and Comfort
	Appointment System

Communication

Establishing Relationships

It was recognized that for adults who have learning disabilities and their carers, community dental appointments were generally positive experiences because of the way in which they were treated with compassion and understanding.

'He gets well attended to when he goes the dentist, he doesn't feel as though he hasn't been attended to, he comes out quite content don't you?' (Joan C4).

There was a clear recognition that spending time with patients during the initial consultation had significant benefits in terms of recognising individual needs and coexisting conditions.

'I think it's you know just to gently build up their or to diminish their fear really,.....I think a little bit of work at the beginning it does pay in the end' (Bill C1).

Giving patients and their carers regular, accurate information about the delays during their visit to the community dental services was important in order to reduce their anxiety and frustration.

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'There were ladies going backwards and forwards in uniforms but no one was saying you're next or it's your turn and I was thinking it seems an awful long time' (Margaret C3).

Specialist Knowledge

It would appear that understanding the specific needs of those with learning disabilities is pivotal in influencing the overall experience for patients and their carers.

'Different disabilities have different things that affect them' (Joan C4).

'One of the bits and pieces of information we get concerning Downs Syndrome people is that they have dental problems and I don't know if that's looked at by the dentist in the respect that he is Downs Syndrome whether they need to do anything different' (Joan C4).

One participant described the effect on the patient if dental staff were not confident about their knowledge on the specific needs of adults with learning disabilities.

'Sometimes they're a bit frightened you know because sort of they don't know what to, and (the patient) will pick up on that if someone's a bit frightened' (Bill C1).

It was clear that the transition from children's dental services into adult dental services had been difficult for some participants.

'Because they come under adult now there won't be as much back up let's put it that way and sort of you know gradually introduce you to it instead of just finishing one day' (Richard C5).

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Participants described the importance of continuity in relation to their experiences of being transferred into adult dental services and this participant suggested that it would be beneficial if there was somebody available who could ease the transition into adult services.

‘We’ve got children you know who are now coming up to going over to adult, you know it’s totally new and there should really be someone, there should be an in between you know where could sort of break you in gently’ (Richard C5).

Dental staff setting aside enough time for explaining procedures to adults with learning disabilities during consultations enhanced the experience of patients and their carers during any treatment.

‘They just really need to talk to (patient) and explain what they’re going to do in advance instead of just taking for granted that he understands what’s going to happen’ (Bill C1).

Attitude and Dignity

Treating adults with learning disabilities as individuals and showing them respect was seen as vital for both carers and the patients.

‘More than anything talk to them and tell them what, you know treat them with respect’ (Bill C1).

Needing to be seen as an individual was evident as was tailoring services to particular needs. *‘They treat her like a real person’* (Sandra C2).

The Appointment System

One carer characterised dental services as flexible and responsive in relation to arranging their appointment.

'The appointments really always suit you and if they don't you can always ring up and change them' (Joan C4).

This carer also identified a lack of recognition from dental staff that dental needs may change as patients became older.

'I would prefer 4 or 3 times a year.....in particular because he has Down's Syndrome....he's getting older now' (Joan C4).

One carer found the current appointment system frustrating as she was not allowed to make the next appointment for her daughter whilst she was at the dental clinic. Instead she had to wait until it arrived through the post and on occasions the appointment didn't arrive at all resulting in a delay in treatment.

'Sometimes we think I'm sure she must be due for an appointment and they have forgot so whether they have just missed her on the list....it would be better if we could be given the appointment on the way out from the dentist and then sent a reminder or letter' (Margaret C3).

Self Care

Community dental services that maintained patient independence was crucial to promoting self confidence and self esteem. One carer referred to advice which was

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given by the dentist in relation to a particular issue that the adult who they support had with brushing their teeth.

'They normally tell him verbally and they give him stuff, like they gave him small, round brushes to get between the gaps in his teeth last time' (Joan C4).

When asked about information or booklets that were available at the dental clinics, one participant remembered some on *'all healthy stuff about how you clean your teeth'* (Sam P3).

However, the provision of information and advice to support self management throughout all stages of their treatment both in writing and verbally, was not evident in all the interviews conducted.

Prevention

Promoting self care can be influenced by the availability of adequate information for individuals on what they need to do during the times in which their usual dental clinic may be closed.

'I've not really thought about a dental emergency I must admit, there's always other emergencies where you would go to the (hospital) and you know but not a dental emergency' (Bill C1).

'I know it's (the dentist) I think and I know it's open every day even Christmas day, 365 days a year' (Margaret C3).

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When asked about information or booklets that were available at the dental clinics, one participant remembered some on, *'all healthy stuff about how you clean your teeth'* (Nicola P3).

For continuity of care it was important that patients and their carers had accurate information about what to do and who to contact in 'out of hours' situations, as clearly some of them didn't

'I've never really thought about that but there again it's something I really should know' (Richard C5).

Experiences

Anxiety and Frustration

It was evident that upsetting incidences which originated outside of current community dental services impacted upon the expectation of patients and carers.

'As soon as he put his gloves on and he went to go near to her she became distressed and upset.' (Margaret C3).

Distressing past experiences for carers and patients had lasting effects and influenced their levels of anxiety during dental appointments.

'I'm getting old and my husband is getting older and it's just putting so much stress on (the patient) because, there was me, my husband and the nurse holding her down while...' (Richard C5).

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There were examples of the frustration that patients and their carers experienced in relation to the length of time they had to wait when they needed to be referred to other specialist dental services for treatment such as extractions.

'This is the problem I have.....you know it's the length of time and what you've got to go through to get anything done' (Richard C5).

The referral system was seen as being complex which resulted in lengthening the time which patients then had to wait to be seen for specialist treatment.

'It's passing on to everybody you know it's just not one particular person who can say oh it's letters that have got to be written and you've got to be referred and then it's all that length of time and then you've got to be fitted in sort of thing you know' (Richard C5).

The Environment

Accessibility

One carer acknowledged that the dental clinic was on a busy main road and that when inside the building signs to the dental clinic were not visible, particularly in the lift indicating which floor dental services were on. One patient couldn't remember seeing any signs, explaining *'well to be honest they haven't got no signs up'* (Cara P2).

They then identified this as important for individuals to ensure that they are certain about where they are going, *'well you know the signs to warn other people, if you know*

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where you're going that's different but other people might not know where they are going' (Cara P2).

Safety and Comfort

A calm atmosphere within the dental clinic helped the patients and carers to relax.

'people rushing around and it's mad busy I think a room set aside for people like (the patient) who need quietness and structure' (Bill C1).

'The pictures were nice and bright and colourful so that was ideal' (Margaret C3).

This was strengthened by one carer who recognized that some adults who have learning disabilities often find new places upsetting or alarming.

'Because he's autistic you know things, strange places are frightening' (Bill C1).

Discussion

This service evaluation provides valuable information on the perceptions of people with learning disabilities and their carers regarding their experiences of dental services. The data were collected from participants in one Trust and caution should be applied when applying the results to services in other areas.

The need to incorporate service users views into service evaluation generally (DoH, 2009a) and for specialist dental services in particular (British Society for Disability and Oral Health, 2012) has been recognized. A major strength of this study is the qualitative approach to evaluating dental services. This enabled and encouraged service users to provide feedback about their experiences.

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In general, participants reported high satisfaction with dental services across a variety of domains. The findings showed interpersonal skills and the competence of the practitioner to be particularly valued by respondents. This is in line with other service evaluations that demonstrate a relationship between satisfaction and these aspects of care (Sun *et al.*, 2010). Specifically, effective interpersonal communication between dental staff and participants were key to establishing and maintaining relationships, providing information, relieving anxiety and showing dignity in our study. In the few instances where dissatisfaction was expressed, it was primarily a result of inadequate communication, e.g. between child and adult services, between the practice and other dental services, or between participants and administration staff making appointments. Transparency of communication in these instances was deemed essential, patients and carers just wanted to be listened to and kept informed. Another aspect of patient satisfaction related to waiting times. Waiting time has been shown to impact on patient satisfaction in terms of service provision and also the dentist-patient relationship (Taylor and Bengner 2004).

The period of time spent waiting for dental treatment is cited commonly by patients as being anxiety-provoking, as it increases the time to think about what will or could happen and the worst-case outcomes (Cohen *et al.*, 2000). Given that people PLD are more likely to suffer from dental anxiety than the normal population (Gordon *et al.*, 1998; Cumella *et al.*, 2000; Martin *et al.*, 2002), extended waiting times could increase this.

The competence of the practitioner was viewed positively and this too was bound up in communicative aspects of care wherein staff who had experience of dealing with PLD or

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had already developed a relationship with the particular patient and/or carer demonstrated confidence in their abilities which resulted in less anxiety for all. Competence and confidence in clinical ability are generic skills required of all health care professionals, including dentists (GDC, 2005, 2009). The results suggest variation in these skills with regards to treating people with learning disabilities.

In terms of access to dental facilities, participants indicated access to buildings was good, but some suggested more specific directions could be provided within some buildings, e.g. in one case the dental clinic was on the 2nd floor and there was little signage to indicate this. Such low cost measures could considerably ease the burden for patients already anxious about seeing the dentist. Access to appointments was also generally good, with one exception which meant the next appointment could not be made at the current visit. In promoting self care, a goal of all dental practice (Petersen, 2008; BSDH, 2012) simple improvements in administration of appointments (Cayirli & Rosen, 2008) for check-ups and the provision of information on contacting emergency dental services could easily address these issues.

One area in which some dissatisfaction was noted was in the movement from child to adult services. Difficulty in transition between child and adult services is not uncommon (DoH, 2008) but there are specific problems that can occur for PLD during this period (Morris, 2000). Whilst there was only one instance of problems in transition in this evaluation improved communication between child and adult services, identification of a

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key person to facilitate transition could be introduced (or better implemented) to reduce these sorts of issues occurring.

Owens *et al.*, (2010) propose access may be defined as having six dimensions:

- Availability: the volume and type of services in the area.
- Accessibility: the physical means by which the client reaches services (this can be both inter and intra building).
- Accommodation: how easy it is for the client to get 'through the door' (for example opening times, flexibility when making appointments).
- Acceptability: the level of satisfaction expressed by the client.
- Appropriate to need: is the service user obtaining what s/he requires from the profession?
- Affordability: the costs of the service, and ability to pay for it.

Further studies are needed to determine whether the experiences detailed in this service evaluation are consistent with those of the wider population of people with learning disabilities who access dental services nationally.

Limitations

This study provides valuable information into adults with learning disabilities and their carer's experiences of dental services, however these findings should be viewed in the context of their limitations. The sample size was small and confined to service users and their carers who were attending two dental clinics within one dental Trust.

Recommendations: In addition to current practice the following should be considered:

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- Acknowledge that adults with learning disabilities are not just recipients of services or advice but may wish to be active participants in their care
- Develop joint strategies and systems to facilitate information exchange during the transition from child to adult services to reduce potential difficulties for PLD and their carer.
- Encourage independence and self care by better promotion of information on self care in an appropriate format within dental services.
- Ensure those managing the care of PLD have the minimum required specialist knowledge and training including staff who support dental services such as administration and clerical teams.
- Provide and/or reinforce information to patients and carers on who is responsible for their care and the 'emergency' or 'out of hours' contact details.
- Develop an implementation plan for the use of qualitative methods for service evaluation including interviews and focus groups with patients and their carers.
- Future studies that are practitioner led will ensure promotion of the project within dental services in order to facilitate larger recruitment and participation numbers.
- Utilise the findings from this project to develop a survey for use with adults who have learning disabilities in order to evaluate the effectiveness of service delivery
- Disseminate the findings from this project to other clinical services in order to demonstrate the transferability of using qualitative methods to explore the 'experiences' of service users.

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