People with learning disabilities, their experiences of dental care: barriers and enablers

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Background

People with learning disabilities often have more untreated carious lesions than the general population. They also have more periodontal diseases, poorer oral hygiene and a higher number of missing or filled teeth (Hall et al., 2011)
Background

A range of policy initiatives aimed to address these inequalities yet a study in 2011 in Sheffield identified that such inequalities remain.

Our study was an applied study commissioned by PHE NE to explore some of the reasons behind these issues locally and identify potential solutions to influence local policy.
Aim: To identify barriers and enablers experienced by people with mild to moderate learning disabilities, and their carers, when accessing community dental services

Study design: A qualitative descriptive design incorporating interviews and focus groups was used (Sandelowski 2000).
Participants

The focus of this study was the personal experiences of people with a mild to moderate learning disability.

However, it was also important to understand these views within a broader context, so the perspectives of formal and informal carers and a service provider were sought to provide a triangulated (Denzin 1978) perspective of access to dental services.
Participant selection

All participants were purposely recruited from community services, including supported living services, residential care and day centres. People were eligible to participate if they had previously been assessed as having a mild to moderate learning disability; were over 18 years old; lived in residential care, supported living or independently within the geographical location of the study; could understand instructions; and were able to provide consent.
Focus groups and individual interviews were used to collect the data, underpinned by a topic guide developed following literature search and incorporating clinical knowledge.

### Table 1: Data collection

<table>
<thead>
<tr>
<th></th>
<th>Focus groups</th>
<th>Interviews</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>PWLD</td>
<td>7 (n=42)</td>
<td>6</td>
<td>48</td>
</tr>
<tr>
<td>Carers</td>
<td>1 (n=5)</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Formal carers</td>
<td></td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Service provider</td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>47</td>
<td>12</td>
<td><strong>59</strong></td>
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Six-stage **data analysis** approach of Braun and Clarke (2006) was used to develop themes from the data – with the specific objective of identifying barriers and facilitators to inform local policy.
Contextual data

• The majority of participants (n=31/48) attended for regular dental care; generally they did not use the Community Dental Service

• Seven participants had dentures. 2 reported visiting dentist regularly; 6 reported not wearing either one of both dentures

• Local water is naturally fluoridated
Barriers
• Past negative experiences
• Perceived lack of need for treatment
• Difficulties with physical access
• Long waits in busy waiting rooms
• Lack of support from informal carers

Facilitators
• Positive relationships with staff
• Recognised value of preventive advice
• Oral health care included in care plans
• Support from carers
last time I went to the dentists was years and years ago. I had to have some teeth out and he was really rough with me. I was a lot younger then but I cried and cried and had loads of pain. There’s no way I’m going through that again. (FG 3 Independent Living)
Barriers: Difficulties with physical access: Long waits in busy waiting rooms

‘I find that sometimes, depending on what type of mood I’m in, I can’t make myself get into the lift. Sometimes I can get in the lift but others I can’t and I have missed appointments’. (Interview C)

‘The longer the residents have to wait the more wound up they become and it can be more difficult for the dentist’. (Interview formal carer)

‘Last time I was at the dentist I didn’t have to wait too long which was a good thing because if I have to wait too long I walk out and don’t see the dentist as I don’t like sitting there with lots of people’. (Interview A)
‘I always had my teeth checked at the day centre but they don’t do it now so I haven’t had mine checked for ages because my mam doesn’t like going to the dentist so won’t take me and I won’t go on my own. She’ll only go if I have a toothache’. (FG 3 Independent Living)

Mum makes the appointment. I go on my own, mum reminds me that I need to go and I go straight there. (FG 2, Independent Living)

I just go when they [the carers] make the appointment and get checked. Someone always goes with me. (Interview 2)
Facilitators: Positive relationships with staff

‘Our dentist is really nice. He talks to my son and also tells me what’s happening and explains things really well. He knows us and we never have any problems.’ (Carers’ FG 2)

‘I don’t like needles but she [the dentist] talked to me about the drills and the needles so I wasn’t frightened.’ (FG 3 Independent Living)
Discussion

• Many of our findings concurred with previous research but there were some notable differences
  – Most participants reported visiting a dentist regularly and had good dental health
  – None regularly used the Community Dental Services
• Good relationships with dental staff were vital
• Formal and informal carers played a pivotal role in facilitating participants to access dental services.
• We found that while carers acted as a facilitator they also sometimes acted as a barrier to participants accessing dental care and maintaining oral health
• Implications are that carers might need support to enable them to undertake this vital role
Discussion

• A number of our participants experienced difficulties fitting in with routine dental surgery processes that a general population might take for granted.

• Our research has highlighted a number of small, reasonable adjustments that can be used to ameliorate some of these environmental factors:
  eg: first appointment of the day = no delays
  Wait in car or outside rather than in waiting room
  Enter surgery via another entrance
Study limitations

- Participants were recruited from one geographical location, where water is fluoridated.
- Self perceptions of dental health were used rather than objective measures.
- Recruitment focused only on people with mild to moderate learning disabilities and therefore might not be applicable to people with other learning disabilities.
Some simple adjustments would require minimal extra resources but have the potential to improve the patient experience and thereby encourage some of this patient group to engage more regularly, or continue to engage, with dental services.