

The oral health of adults with learning disabilities: A secondary analysis of the Adult Dental Health Survey 2009

James Bird¹, Zoe Marshman², Kate Jones³ and Sarah R Baker²

¹Community and Special Care Dentistry, Sheffield Teaching Hospitals NHS Foundation Trust, UK; ²School of Clinical Dentistry, University of Sheffield, UK; ³Office for Health Improvement and Disparities, Department of Health & Social Care, UK

Objectives: Adults who have learning disabilities are a vulnerable group, little is known about their oral health and how this affects their quality of life. The aims of this secondary analysis of data from the 2009 Adult Dental Health Survey (ADHS) were to describe the oral health status of adults with learning disabilities, determine if severity of learning disability is associated with oral health and identify some of the methodological complexities of working with this population. The survey yields the most recent representative data on the oral health of adults with learning disabilities in England and importantly, contains information about oral health related quality of life (OHRQoL).

Basic research design: Secondary analysis of data from a supplemental survey of adults with learning disabilities collected alongside the 2009 ADHS. **Participants:** 607 participants with a diagnosed learning disability aged 18 years and over. **Results:** Adults with learning disabilities had similar levels of active dental caries, fewer natural teeth, and fewer fillings than comparable participants from the general population. Self-reported oral and general health were worse for adults with learning disabilities than the general population. Possible associations between the severity of learning disability and the numbers of decayed, missing or filled teeth were identified. However, large amounts of missing data limited the analysis. **Conclusions:** There are important questions relating to the accessibility of existing self-reported oral health questionnaires and the reliability of proxy-reported questions about OHRQoL that should be addressed to give a fuller picture of the oral health of adults with learning disabilities.

Keywords: oral health, dental health survey, health-related quality of life, adult learning disabilities

Introduction

There are approximately 930,000 adults with a learning disability in England, representing roughly 1.5% of the population (Public Health England, 2016). The term ‘learning disability’ is used to describe people with “arrested or incomplete development of the mind characterised by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e., cognitive, language, motor and social abilities” (World Health Organisation, 2019). Typically, mild learning disability is used to describe people who are able to live independently with low levels of support; moderate learning disability describes those who live with a degree of independence, for example in a group home; and severe learning disability describes those with higher support needs including for daily self-care. Those with profound learning disabilities are likely to need support with all activities of daily living and may have additional physical and sensory support needs. On average, adults with learning disabilities have worse health outcomes, worse physical and mental ill health (Krahn and Fox, 2014) and are more likely to use a more extensive range of hospital services than adults who do not have learning disabilities (Hatton *et al.*, 2016).

Typically, adults with learning disabilities have worse oral hygiene, more severe periodontal disease, more missing teeth and more untreated dental caries than adults who do not, although the prevalence of caries is usually similar to the general population (Anders and Davis, 2010; Wilson *et al.*, 2019). The most recent Adult Dental Health Survey

(ADHS), conducted in 2009, showed that the oral health of the general population had improved over time; yet, less is known about trends in the oral health of adults with learning disabilities.

There has been much literature on how poor oral health affects quality of life in the general population (Peres *et al.*, 2019) but less research has been conducted with adults with learning disabilities. A study in Brazil suggested that periodontal pocketing, dental treatment need and the need for a dental prosthesis were associated with reduced oral health-related quality of life (OHRQoL) amongst 11-29 year olds with learning disabilities (Alves *et al.*, 2016) and these findings are supported by similar studies from Germany (Hillebrecht *et al.*, 2019) and Portugal (Couto *et al.*, 2018a). Less is known about the situation in the UK.

Many studies have used a proxy-reported measure of OHRQoL (e.g., parent/carer/guardian reports). These are sometimes appropriate as adults with learning disabilities may have communication impairments and so may not be able to self-complete commonly used OHRQoL measures. However, the use of self-reported measures is preferred, as whilst proxies may be able to accurately gauge how physical domains affect health related quality of life, judging how social or emotional domains impact quality of life is more challenging from a third person perspective, particularly when participants have communication problems. Differences between self-reported scores and proxy-reported scores (the so-called inter-rater gap) in relation to health more generally, mean that care must be taken when interpreting quality of life measurements collected from different respondents (Khadka *et al.*, 2019).

The ADHS is an epidemiological survey conducted approximately every ten years in England, Wales and Northern Ireland. The design, sampling methods and consent requirements exclude some groups from participation and these groups often include vulnerable adults. To be more inclusive, supplementary adult sub-group surveys (SASGS) were conducted alongside the 2009 ADHS to capture comparable data from three specific subgroups: adults with learning disabilities, adults requesting, referred for or using domiciliary services and adult users of out of hours dental services.

This secondary analysis of the supplementary survey of adults with learning disabilities aimed to address three questions: (i) how does the oral health of adults with learning disabilities compare with the general population? (ii) does severity of learning disability have an impact on oral health? and (iii) what, if any, are the challenges of conducting this type of survey with this population?

Methods

We secondary analysed data collected in the supplementary adult sub-group survey of adults with learning disabilities. The survey was conducted alongside the main 2009 ADHS using a protocol based on that for the Office for National Statistics 2009 ADHS. Full details have been published (The NHS Health and Social Care Information Centre, 2009).

Briefly, the survey consisted of two parts, a structured interview and a clinical examination, both conducted at the participant's homes or at day centres. The questionnaire contained 73 questions covering demographics, oral health status, dental attendance, oral health behaviours, dietary behaviours and a selection of questions about OHRQoL based on the oral health impact profile (OHIP) (Slade and Spencer, 1994) and oral impact on daily performance (OIDP) (Adulyanon *et al.*, 1996) questionnaires. Both parts of the survey were completed by a dentist and an administrative support worker who had both been trained in the survey protocol. A simplified examination was completed as it was felt that participants might not tolerate the full examination used in the ADHS. This simplified examination was sufficiently similar to the full ADHS examination to allow comparisons between data sets.

The inclusion criteria were adults aged 18 or over with a recorded learning disability who were able to understand the rationale for the survey or if they lacked mental capacity for this had assent given by a relative or carer. In addition, the participant needed to be able to provide answers for the questionnaire or have a proxy who could answer on their behalf. Severity of learning disability (mild, moderate or severe) was determined in the original dataset by using the participants' recorded diagnosis which could be based on either local or national criteria. For the clinical examination, participants needed to have one or more natural teeth and be able to cooperate enough to allow the safe completion of the examination.

A number of computed variables were calculated from the decayed, missing, filled teeth (DMFT) data collected in the examination. The care index (proportion of teeth with decay or history of decay that have been treated by restoration) was calculated by: $F/(D+M+F)$ and the restorative index (the proportion of decayed and filled teeth that have been filled) was calculated as: $F/(F+D)$.

As the care index includes extracted teeth, comparison of these two measures can show if decayed teeth in one group is more likely to be treated by extraction. Unmet treatment need was quantified as the proportion of decayed teeth of the total DMFT score: $D/(D+M+F)$.

Descriptive summary statistics (frequency, mean, 95% confidence intervals) were produced to enable comparison with data from the 2009 ADHS. Correlations between the severity of LD and clinical and computed variables were identified with Spearman correlations.

Results

In total, 607 participants were recruited (Table 1). Most completed both the examination and questionnaire, although, almost 30% did not complete either part. Clinical examination data were available for 387 participants, 339 completed the examination fully, 35 examinations were partially completed due to participants being unable to cooperate fully and 13 withdrew their consent after starting the examination. The proportion of those not completing the full examination increased as the severity of learning disability increased.

Questionnaire data from the 427 participants who either fully or partially completed the questionnaire were analysed. Participants were asked if they had a recorded severity of learning disabilities, but 77 participants had no data recorded for this question. The questionnaire was self-completed by 53% of participants; those with a mild learning disability were more likely to self-complete the questionnaire than those with a severe learning disability (86% vs 10%).

The questionnaire comprised 63 questions. A group of 233 participants (54.5% of the total) were missing responses for the same 24 questions. There were no common factors except that all 233 participants were from three of the six participating strategic health authorities. Owing to the large amounts of missing data, these 24 questions were excluded from the analysis.

Of those who completed both parts, the severity of learning disability was distributed evenly across the three categories (mild/moderate/severe). However, those who only completed the questionnaire were more likely to have a moderate or severe learning disability. Similar numbers of males and females completed both the examination and questionnaire but amongst those who only completed the questionnaire 68.9% were male. Most participants were White British. Demographic data were not collected for those who did not complete the questionnaire.

As can be seen from Table 2, adults with learning disabilities had fewer natural teeth present than those in the 2009 ADHS (22.9 vs 25.7 teeth), but the presence of a denture was similar (11.0% vs 13.0%). Proportionately fewer adults with learning disabilities had filled teeth (69.2% vs. 84.0%) and those that had filled teeth had fewer filled teeth than the 2009 ADHS participants (5.0 vs 7.2 filled teeth). Similar proportions had active caries (37.0% vs 31.0%) and those who had caries had similar numbers of affected teeth compared to the general population (3.1 vs 2.7 teeth). For all age groups up to 55-64 years, adults with learning disabilities with at least one carious tooth tended to have more carious teeth than similarly aged 2009 ADHS participants. The opposite pattern was seen for those in age groups 55-64 and over 65. Fewer adults

Table 1. Characteristics of the 607 adults with learning disabilities.

| | <i>Examination and questionnaire n = 382 (%)</i> | <i>Questionnaire only n = 45 (%)</i> | <i>Examination only n = 5 (%)</i> | <i>Neither n = 175 (%)</i> | <i>Total, n = 607 (%)</i> |
|-------------------------------|--|--|---|------------------------------------|-----------------------------------|
| Gender | | | | | |
| M | 49.2 | 68.9 | | | 36.1 |
| F | 47.1 | 28.9 | | | 31.8 |
| Missing | 3.6 | 2.2 | 100.0 | 100.0 | 32.1 |
| Age | | | | | |
| 18-24 | 12.6 | 6.7 | 20.0 | | 8.6 |
| 25-34 | 21.7 | 6.7 | 40.0 | | 14.5 |
| 35-44 | 25.7 | 2.2 | 20.0 | | 16.5 |
| 45-54 | 21.5 | 28.9 | | | 15.7 |
| 55-64 | 11.8 | 17.8 | | | 8.7 |
| 65+ | 5.8 | 35.6 | | | 6.3 |
| Missing | 1.0 | 2.2 | 20.0 | 100.0 | 29.8 |
| Ethnicity | | | | | |
| White British | 80.4 | 84.4 | | | 56.8 |
| Asian | 4.5 | 8.8 | | | 3.5 |
| Black | 2.4 | 0.0 | | | 1.5 |
| Other | 7.9 | 4.4 | | | 5.3 |
| Missing | 5.0 | 2.2 | 100.0 | 100.0 | 32.9 |
| Severity of LD | | | | | |
| Mild | 25.4 | 6.7 | | | 16.5 |
| Moderate | 29.3 | 42.2 | | | 21.6 |
| Severe | 26.7 | 37.8 | | | 19.6 |
| Missing | 18.6 | 13.3 | 100.0 | 100.0 | 42.3 |
| Questionnaire completed by | | | | | |
| Volunteer | 55.8 | 28.9 | | | 37.2 |
| Someone else | 41.6 | 66.7 | | | 31.1 |
| Missing | 2.6 | 2.2 | 100.0 | 100.0 | 31.6 |

with learning disabilities reported brushing their teeth twice a day or more compared to 2009 ADHS participants (55.3% vs. 75.0%). Self-reported oral and general health were both worse for adults with learning disabilities than 2009 ADHS participants. OHRQoL was similar for adults with learning disabilities and 2009 ADHS participants.

Table 3 shows how all severities of learning disability had similar numbers of teeth present. However, those with a severe learning disability had fewer filled or decayed teeth than those with a less severe learning disability. There were almost no differences between the groups for the amount of calculus, number of functional contacts or presence of unrestored anterior spaces. The restorative index, care index and unmet treatment need scores decreased as severity of learning disability increased.

Most participants (or their proxies) reported having very good or good oral health. The distribution of responses for mild and moderate learning disabilities were very similar (Figure 1) but those with severe learning disabilities had more negative ratings of their dental health than other participants. Responses to the self-reported general health question were more positive with a greater proportion of participants rating their general health as good or very good.

The questionnaire included seven questions related to oral health impacts on day-to-day life, four of these questions had large amounts of missing data and were excluded from the analysis. The included questions revealed how in the last year, most participants reported never or hardly ever having painful aching in their mouth, finding it uncomfortable to eat, or being self-conscious or embarrassed because of problems with their mouth. As severity of learning disability increased the proportion of participants not answering or having missing data increased, particularly for the question relating to embarrassment.

Adults with mild learning disabilities were less likely to brush their teeth (or have them brushed) twice a day or more compared to those with moderate or severe learning disabilities (46.0% vs 61.1% vs 61.3%). These responses are lower than the comparable figure from the 2009 ADHS (75%).

Very weak correlations were found between severity of learning disability and the presence of an unrestored space in the lower anterior segment ($r=0.120$, $p<0.05$), having pain in the mouth ($r=0.121$, $p<0.05$) and the presence of one or more of the following: an open pulp, ulceration, fistulae or an abscess (PUFA lesions) ($r=0.112$, $p<0.05$).

Table 2. Oral health of 387 adults with learning disabilities compared with 2009 ADHS.

| | <i>SASGS</i> (95% CI) | <i>2009</i> <i>ADHS</i> |
|--|--------------------------|----------------------------|
| Number of teeth present (n) | 22.9 (22.1, 23.6) | 25.7 |
| Sound teeth (n) | 17.7 (16.9, 18.6) | 17.9 |
| Decayed teeth (n) | 1.1 (0.9, 1.4) | 0.8 |
| 1 or more filled teeth (%) | 69.2 (64.2, 73.9) | 84.0 |
| Mean number of filled teeth amongst people with at least 1 filling (n) | 5.0 (4.5, 5.4) | 7.2 |
| 1 or more decayed teeth (%) | 37.1 (32.1, 42.3) | 31.0 |
| Mean number of carious teeth amongst those with at least one carious tooth (n) | 3.1 (2.6, 3.6) | 2.7 |
| 21 or more natural teeth (%) | 72.4 (67.5, 76.9) | 84.0 |
| Denture present (%) | 11.6 (8.7, 15.0) | 13.0 |
| One of more PUFA lesion (%) | 6.5 (4.3, 9.2) | 7.0 |
| Visible calculus in one of more sextants (%) | 73.9 (69.1, 78.3) | 68.0 |
| Brushing twice or more per day (%) | 55.3 (50.5, 60.1) | 75.0 |
| Brushing once per day (%) | 22.5 (18.6, 26.7) | 23.0 |
| Self-reported mouth pain (%) | 7.5 (5.3, 10.6) | 9.0 |
| Self-reported general health - very good or good (%) | 68.3 (63.7, 72.7) | 81.0 |
| Self-reported dental health - very good or good (%) | 54.9 (50.0, 59.6) | 71.0 |
| Painful aching from the mouth - occasionally, fairly often or very often (%) | 23.4 (19.5, 27.7) | 22.0 |
| Uncomfortable eating because of problems with their mouth - occasionally, fairly often or very often (%) | 19.4 (15.8, 23.5) | 22.0 |

Discussion

This secondary analysis found several key differences in the oral health of adults with learning disabilities compared to participants from the 2009 ADHS and in general, the oral health of adults with learning disabilities was worse. Typically, they had fewer natural teeth and slightly more decayed teeth than comparable participants from the 2009 ADHS. Furthermore, both self-reported oral and general health were worse for adults with learning disabilities.

Past studies (Anders and Davis, 2010; Wilson *et al.*, 2019), have shown that adults with learning disabilities typically have fewer teeth than those without and this survey mirrored those findings. Some adults with learning disabilities may be unable to cooperate with dental care and/or be unable to accept long or complex treatment and this may explain the higher prevalence of extractions. Furthermore, people who cannot accept treatment under local anaesthetic may require general anaesthesia (GA). For these people, treatment planning must aim to reduce the likelihood of the need for a repeat dental GA (Geddis-Regan *et al.*, 2022) and this may lead to more radical treatment being carried out. Whilst extracting a tooth of questionable prognosis removes the uncertainty of what might happen if the tooth was restored, it condemns the person to a less functional dentition and may also deliver worse cosmetic outcomes, which could have wider impacts on OHRQoL.

Despite having fewer teeth than the 2009 ADHS participants, proportionately more participants with learning disabilities reported having oral pain in the last year, but were less likely to feel embarrassed by their teeth and reported fewer problems eating. These oral health impact findings are similar to those from a postal survey study in which adults with learning disabilities completed a questionnaire that had been developed in conjunction with learning disability self-advocates and other experts (Owens *et al.*, 2017). The survey was designed to be

Table 3. Dental status by severity of LD among 387 adults with learning disabilities.

| | Severity of learning disability | | | | |
|-------------------------------|---------------------------------|-----------------------|---------------------|----------------------|--------------------|
| | Mild Mean (SD) | Moderate Mean (SD) | Severe Mean (SD) | Missing Mean (SD) | Total Mean (SD) |
| Total number of teeth present | 23.4 (6.4) | 22.2 (7.9) | 22.9 (7.2) | 23.7 (6.7) | 23.0 (7.1) |
| Sound teeth | 16.6 (8.0) | 17.4 (8.6) | 18.9 (9.0) | 18.2 (7.4) | 17.7 (8.3) |
| Decayed teeth | 1.5 (2.6) | 1.1 (2.2) | 0.6 (1.9) | 1.3 (2.6) | 1.1 (2.3) |
| Missing teeth | 8.7 (6.4) | 9.6 (7.9) | 8.9 (7.2) | 8.3 (6.7) | 8.9 (7.1) |
| Filled Teeth | 4.5 (4.2) | 3.2 (3.7) | 2.3 (3.0) | 3.6 (3.2) | 3.4 (3.7) |
| DMFT | 14.5 (7.8) | 13.8 (8.6) | 11.7 (8.2) | 13.2 (7.0) | 13.4 (8.0) |
| Restorative index | 59.1 (42.8) | 49.3 (44.4) | 46.3 (47.1) | 65.7 (38.4) | 54.4 (44.0) |
| Care Index | 29.8 (28.2) | 21.8 (24.9) | 18 (24.3) | 29 (23.4) | 24.4 (25.8) |
| Unmet clinical needs | 10 (18.2) | 8.5 (16.1) | 4.1 (10.5) | 11.2 (19.6) | 8.4 (16.5) |

There were no significant correlations between any of the variables and severity of learning disability at the 0.05 level.

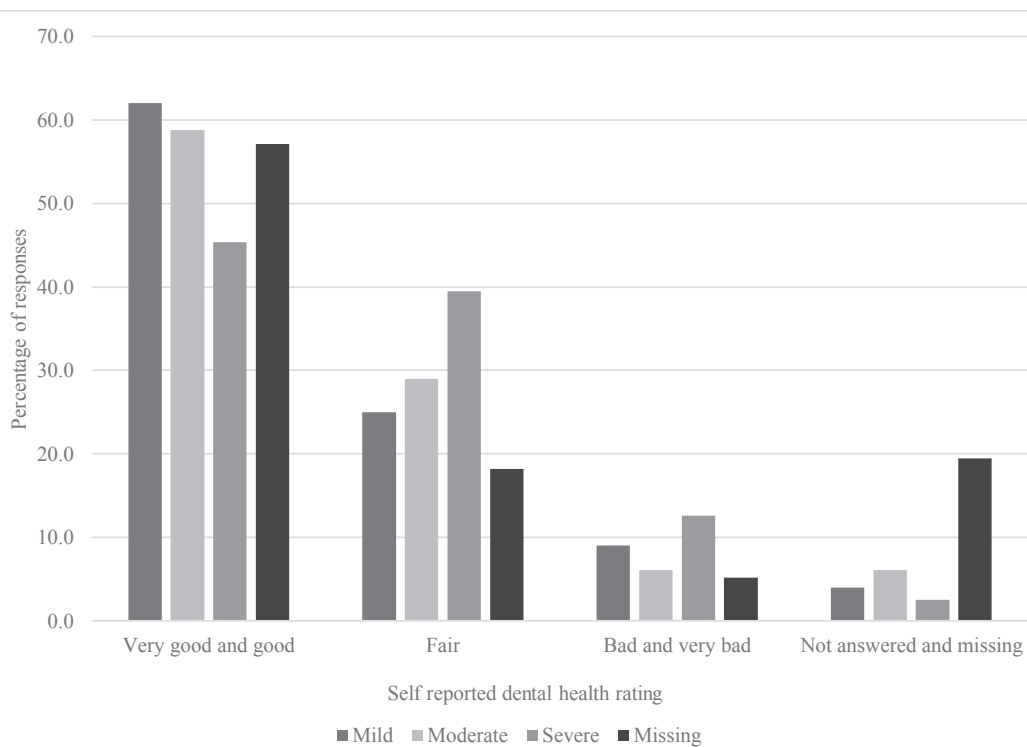


Figure 1. Self-reported dental health by severity of learning disability among 427 adults with learning disabilities.

self-completed and was formatted in an Easyread style with photos and photo symbols. The authors found that adults with learning disabilities reported slightly better OHRQoL than those without, however as the study did not capture any clinical data it is not possible to comment on any associations between OHRQoL and oral health status or clinical treatment need.

Similar number of sound, decayed or filled teeth were seen across the different severities of learning disability. This may reflect the dental status of the different groups however, there is also the possibility of a type II error as a result of the relatively small sub-group sizes. Additionally, severity of learning disability was based on a self-reported recorded diagnosis made according to local or national criteria, but terminology relating to learning disabilities and the classification of severity of disease has changed considerably over time so there is potential for overlap between the groups.

Adults with mild learning disabilities are usually more independent than those with severe learning disabilities so have more freedom to make their own choices about dental attendance, tooth brushing and dietary choices etc., yet may not have full understanding of the consequences of their decisions (Caton *et al.*, 2012). Additionally, they may live alone or with family in the community and lead relatively ordinary lives (Hatton *et al.*, 2016), so reaching them for health improvement and healthcare interventions can be more challenging.

Learning disability specific patient reported outcome measures have been developed including adaptations of the 14 and 5 item versions of OHIP. Couto *et al.* (2018b) (2018a) modified a valid and reliable OHIP-14 for use with Portuguese adults with mild learning disabilities and demonstrated that missing teeth and reporting a greater need for dental treatment were associated with worse OHRQoL. Hillebrecht *et al.* (2019) developed a German

5-item version of OHIP with 3 response options and showed that dental treatment under GA led to improvements in OHRQoL for adults with learning disabilities. No validated, English language learning disability specific OHRQoL measure exists and so it can be challenging to reliably measure OHRQoL in this population.

There are a number of limitations to this secondary analysis. First, there were considerable missing data from the supplementary survey of adults with learning disabilities, some of which could be explained (e.g. participants withdrawing consent) but explanations for most of the missing data were not known. The presence of a group of participants all missing data for the same non-consecutive 24 questions does not seem random and meant that a large number of questions had to be excluded from our analysis. The excluded questions included four of the seven questions about OHRQoL and even amongst the included self-report questions many had in excess of 20% of responses missing. The wording of the included questions about OHRQoL was unmodified from the original OHIP and ODP items. Adults with learning disabilities struggle to answer five-point Likert scales and so changing the responses to three-point scales may have improved data collection. Furthermore, Likert scales are less reliable when used by adults with moderate or severe learning disability, especially if they do not feature photo symbols. Self-reported data are an important resource that give participants the chance to express their own opinions, yet many participants needed assistance in completing this questionnaire. Whilst some self-report measures have shown validity when used by a proxy this has not yet, to our knowledge, been done for OHIP. Another limitation is the relatively small number of participants. Recruitment is often challenging when conducting research with adults with learning disabilities (Shepherd, 2020) and strategies to improve it have

been described (Nicholson et al., 2013). This secondary analysis has also shown how once recruited to the study, changes in participant cooperation or behaviour can lead to high dropout rates and act as a potential source of bias. Person-centred approaches to research, including a degree of flexibility to meet individual participant's specific needs have been suggested to improve retention in hard-to-reach groups. However, recruitment and retention of adults with severe and profound learning disabilities is likely to remain a challenge that will restrict the generalisability of any findings. Future studies should be designed in collaboration with adults with learning disabilities to minimise the impact of these difficulties. Another factor affecting the generalisability of the findings is that most participants identified as being White British. Whilst the proportions of ethnicities are broadly in line with the make-up of the British population, the small sample size restricts generalisations about participants from minority groups. Lastly, whilst the data are the most up to date that could be accessed, they were collected in 2010/2011 and so the patterns of disease and oral health impacts seen in this study may not reflect the current oral health status of this population. Despite this, these data are an important benchmark against which future studies can compare their findings.

In conclusion, this secondary analysis highlighted some of the oral health problems faced by adults with learning disabilities and has shown some of the challenges they face in ensuring their needs are understood. There are clear differences in the oral health of adults with learning disabilities compared to those who do not have learning disabilities, and this survey revealed possible associations between the severity of learning disability and the numbers of decayed, missing or filled teeth. There are important questions relating to the accessibility of existing self-report oral health questionnaires and the reliability of proxy reported questions about OHRQoL which need to be addressed to give a fuller picture of the oral health of this population. There is a need to improve the oral health of this group to tackle the inequalities they face. Inclusive research methods, including the co-design of new questionnaires by adults with lived experience of learning disabilities should be used to ensure the views and oral health needs of adults with learning disabilities are captured in research.

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