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Dental Public Health in Action

The oral health of people with learning disabilities - a user-friendly questionnaire survey

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Impetus for action: To conduct a user-friendly questionnaire survey of the oral health and service needs of adults with learning disabilities. ***Solution:*** Researchers collaborated with local self-advocacy services to develop a questionnaire adapted from one used in a regional postal survey. The questionnaire, which covered dental status, oral health and dental services use, was sent to a random sample of people from the learning disability case register. ***Outcome:*** Of 2,000 questionnaires mailed, 117 were returned undelivered and 625 were completed (response rate 31.3%). The self-reported dental status of people with learning disabilities appeared similar to that of the 2008 postal survey of the general population in Sheffield. The major difference in dental status was 11.5% of people with learning disabilities wore upper dentures and 7.2% wore lower dentures, compared to 21.2% and 12.1% of the general population in Sheffield. ***Challenges:*** Using the case register as a recruitment instrument may have excluded people with learning disabilities not registered. Time and finances only permitted one mailing. Analysis on the basis of deprivation could not be conducted. ***Future implications and learning points:*** Contrary to current practice, it is possible to include people with learning disabilities in oral health surveys. A multidisciplinary team was essential for enabling the progression and implementation of inclusive research and for people with learning disabilities and their supporters to engage meaningfully. This level of collaboration appears necessary if we are committed to ensuring that people with learning disabilities and their supporters are made visible to policy and decision-makers.

Public Health Competencies being illustrated: oral health surveillance, dental public health intelligence, communication.

Key words: *learning disabilities, self-report, oral health, questionnaires, England*

Initial impetus for action

Sir Jonathan Michael's 2008 inquiry into access to healthcare for people with learning disabilities identified that they experience high levels of health need which are currently not being met (Michael, 2008). The inquiry was supported by *Valuing People Now* (Department of Health, 2009) which suggested that progress towards provision of wider access to healthcare is limited for the majority of people with learning disabilities, particularly in relation to general primary health care. A major obstacle to progress is the lack of information about people with learning disabilities and their experiences of healthcare (Hatton *et al*., 2005). This is despite the Health and Social Care Act 2001 (Section 242) placing a duty on the NHS to involve and consult patients and the public at all stages of the planning and delivery of services, and in decisions affecting their operation.

Healthcare research argues that failing to ask disabled people for their views and to take them seriously, has meant that services and indeed policies have been built and delivered in ways that are not accessible or acceptable to people with learning disabilities (Bigby, 2004; Swain and French, 2004; Barnes and Mercer, 1997). With the development of self-advocacy reinforced by the disability movement and recent progress in health policy (DoH, 2001; 2003, 2004, 2007a,b), people with learning disabilities are now beginning to be regarded as informative, critical and reliable service evaluators (Sternfert-Kroese *et al.,* 1998). More recently, there is growing evidence of user involvement in research involving people with learning disabilities (Richardson, 2002; Ham *et al.,* 2004; Grant and Ramcharan, 2007; McClimens *et al*., 2007).

National health and oral health surveys such as Health Survey for England and the ten-yearly national dental health surveys have attempted to gained the public's perspectives on their own health and oral health, through the use of standardised measures. Traditionally, these surveys have included only adults residing in 'normal residential households' with no special support arrangements for adults with learning disabilities (Glover *et al.,* 2011). A few surveys have considered the oral health of children or adults with learning disabilities but the studies that have been conducted have focused on normative assessment of clinical status (Cumella *et al*., 2000; Davies *et al.,* 2008; Hennequin *et al.,* 2000; 2008). A recent systematic review identified that the perspectives of people with learning disabilities has been neglected in oral health research (Whelan *et al*., 2010).

Therefore, the aim of this study was to enable people with learning disabilities in Sheffield to participate in a postal questionnaire of their oral health and dental service needs.

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Solution suggested

A steering group was established to inform the design of the questionnaire, discuss sampling methods and analysis and aid in the interpretation of the results and their dissemination. Although the steering group did not include adults with learning disabilities themselves because of time issues and travel logistics, their representatives from self-advocacy groups, Sheffield's learning disability partnership board, and the People's Parliament, were members. The researchers also spent time in the field developing further links and networks to enable a more inclusive approach to occur, for example, linking with the learning disability case register for Sheffield, speaking to and attending self-advocacy groups, the People's Parliament monthly meetings and attending Mencap weekly meetings.

A questionnaire was adapted from one used in a regional survey and included:

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

The format and wording of questions were amended slightly to make them clearer for adults with learning disabilities (see online-only Appendix 1). For example, 'Do you never go to the dentist' was amended to 'Never seen a dentist'. Photographs were added in the form of an accompanying explanation sheet, using Photosymbols 3®. The explanation sheet was developed and piloted with people with learning disabilities through self-advocacy groups and 'Signpost Sheffield', run by Sheffield City Council for people with learning disabilities, families, carers and staff. Previous research has indicated that photographs increase the frequency of responses (March, 1992; Norah Fry Research Centre, 2004), therefore the explanation sheet was designed to enable completion of the questionnaire directly by people with learning disabilities or, at least for them to be included in its completion with their supporters or carers (see Appendix 1). An open section was added for participants to provide additional information or to raise issues not addressed by the questionnaire.

Key information required included the proportion of people with learning disabilities who had difficulty accessing dental services and those perceiving they needed dental care.

The accessible population included all adults (aged 18 and over) on the Sheffield learning disabilities case register (n=3,080). As the register is confidential, the researchers relied on the case register team to randomly select 2,000 participants and post the questionnaires. The NHS logo was used on the questionnaire and the letter was addressed from the case register to reassure people with learning disabilities about confidentiality. Stamped addressed envelopes were provided. Only one mailing was used because of the constraints of finance and confidentiality.

Approval was obtained from an NHS ethics committee ref: 10H/1310/53.

Actual Outcome

Of the 2,000 questionnaires mailed 117 were returned undelivered by the post office and 625 were returned completed in their entirety, representing a response rate of 31.3%. Over one quarter (27.7%) were completed by the individual, 30.9% by a paid carer, 23.4% by an unpaid carer and 17.4% were completed by someone else.

Of the 625 who responded, 353 (56.5%) were male and 272 (43.5%) were female. The mean age was 40.2 years and ranged from 18 to 87 years.

The results for people with learning disabilities were compared to the results of the 2008 oral health postal survey of people in Sheffield (Yorkshire and Humber Public Health Observatory, 2009).

Table 1. Comparison of results from postal survey of oral health of adults with learning disabilities in Sheffield with results of the 2008 postal survey of general adult population in Sheffield

	Adults with learning disabilities in Sheffield n= 625, (%)	*Adults in general population in Sheffield n= 10,864, (%)*
Dental status		
Having one or more natural teeth	93.6	93.3
Denture wearing - upper	11.5	21.1
Denture wearing - lower	7.2	12.1
Impact of the mouth on everyday life		
Health of the teeth, lips, jaws and mouth overall; fair to v.poor	31.2	23.8
Frequency of pain in last 12 months	27.7	30.8
Frequency of discomfort when eating in last 12 months	26.6	33.8
Frequency of being self-conscious in last 12 months	13.1	29.9
Perceived need for dental treatment		
Need dental treatment	19.3	21.1
Did not know whether needs treatment	34.7	25.5
Dental attendance		
Last visited dentist within two years	86.0	83.5
Attend dentist for regular check-ups	74.7	72.3
Attend only when having problems	11.6	16.9
Never seen a dentist	3.3	3.2
Difficulties getting routine dental care	13.2	19.5
Difficulties getting care for urgent problems	10.5	16.0

The self-reported dental status of people with learning disabilities appeared similar to that of the general population in Sheffield. The main differences were that fewer people with learning disabilities reported wearing dentures (11.5% for upper dentures and 7.2% for lower dentures), compared to 21.2% and 12.1% of the general population in Sheffield.

Compared to the general population in Sheffield, more people with learning disabilities reported not knowing whether they needed treatment (34.7% vs. 25.5%), although a slightly higher proportion of them reported regularly attending the dentist for a check-up than the general population (74.7% vs. 72.3%) and fewer reported attending only when they had problems (11.6% vs. 16.9%). Difficulties gaining access to routine dental care were reported by 13.2% of participants with learning disabilities compared to 19.5% of the general 2008 Sheffield population. The questionnaire also enquired about difficulties accessing dental care when people were having problems with their teeth or mouths. Overall 10.5% of participants reported having such difficulties compared to 16.0% of the same general population. The most commonly reported reason for difficulties were 'scared of dentists', 'difficult to make the journey to the dentist' and 'no local dentist'. These reasons were explored in more depth in the qualitative study that ran concurrently and are different from those most commonly reported by adults in the Sheffield population of 'treatment too expensive', 'dentists only treating privately' and 'no dentists taking patients'. The reasons fit with access to routine care; the most frequently reported barriers to care when having problems were 'scared of dentists' which was often based on prior experiences or lack of continuity of care and 'difficult to make the journey to the dentist' which occurred most often for people who had higher support needs and required a carer and transportation.

The responses from people with learning disabilities and their carers indicated that they engaged more regularly with dental services than the rest of the local population in Sheffield. What the study could not do was identify any differences between adults with differing levels of learning disability; mild, moderate or profound. This may be pertinent because people with profound learning disabilities often have other co-morbidities which can exert an impact on oral health, this may increase the issues regarding access to care and need for dental treatment.

The data suggested that even though the proportion of people with learning disabilities who were dentate (93.6%) was very similar to the rest of the population of Sheffield (93.3%), lower numbers wore dentures. This may be because some people may be unable to tolerate wearing dentures or there may have been problems in making dentures, or it could be that dentures were not offered as a choice or quite simply that people did not want them. Reasons for visiting the dentist were identical to the rest of the population but varied, with dental anxiety and transport problems being more common for people with learning disabilities, which are supported by existing literature (Owens *et al*., 2011).

Challenges addressed

Firstly, registration on the disability care register is voluntary and it is possible that using the case register as a recruitment instrument may have excluded people with learning disabilities who were not registered. Secondly, due to financial, time and logistical limitations only one posting was possible and the response rate may have increased following a further mailing. Thirdly, analysis on the basis of deprivation was not conducted due to the frequent moves, which are often enforced, from area to area and experienced by many adults with learning disabilities (Barnes and Mercer, 2010).

Future implications and learning points

It is possible to include people with learning disabilities in oral health surveys, but it requires careful planning, a multidisciplinary team, including a researcher who has worked extensively with people with learning disabilities and with the UK social model of disability, knows the issues around consent, participation, and the research methods that can be employed. This level of knowledge in the team is essential for enabling the progression and implementation of inclusive research.

The concepts and the methodology used in this study, particularly developing the explanation sheet using Photosymbols 3® involved an iterative process with extensive engagement with those who worked alongside people with learning disabilities including Signpost Sheffield and self-advocacy groups. Although this level of engagement was time consuming and had implications for the costing of similar projects in the future, it ensured people with learning disabilities and their carers were able to engage meaningfully with the survey and similar mechanisms could be used to ensure people with learning disabilities are made visible to policy and decision makers.

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Annexe 1: Adult Oral Health Questionnaire

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

You need to fill in your answers on the other sheet.

You might need someone to help you to do this.

SECTION 1: This part asks questions about you

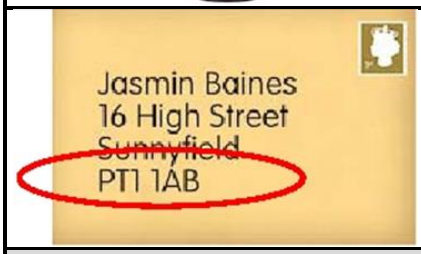

Male Female

Q1. What is your sex?

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

Q2. How old are you (in years)?

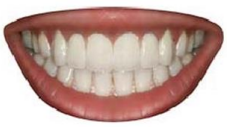
You need to write your age in the box.

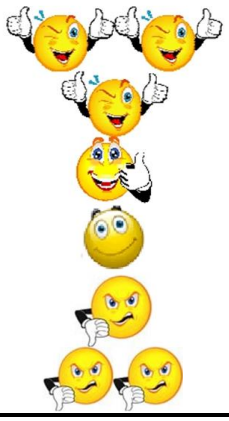


Q3. What is your postcode?

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

SECTION 2: This part asks questions about how healthy your mouth is





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

You need to put a tick ☑ in the right box:

☐ Excellent

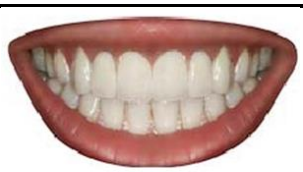
☐ Very good

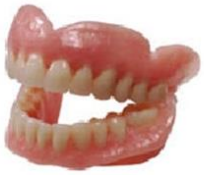
☐ Good

☐Fair

☐ Poor

☐ Very poor

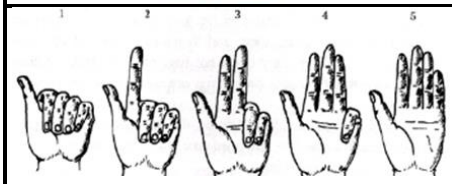




Q5. Have you still got some of your own (natural) teeth?

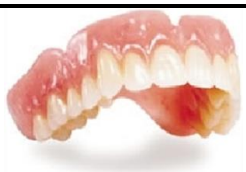
If some of your teeth are your own (not false), you need to tick the 'yes' box.

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



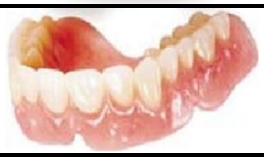
Q6. Sometimes teeth fall out, or have to be taken out. How many of your own teeth do you still have?

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



Q7. Are your top teeth false teeth?

Put a tick ☑ in the right box



Q8. Are your bottom teeth false teeth?

Put a tick ☑ in the right box

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

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

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

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

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

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

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

SECTION 3:	This part asks you questions about visiting the dentist
	**Q12. This question is about how long ago your last visit to the dentist was.** You need to tick ☑ the right box to say how many years ago it was.
	**Q13. This question is about why you go to the dentist.** ☐ Do you go to have a **regular check-up**? - this means you go once every year or two years to have your teeth checked ☐ Do you go to have an **occasional check-up**? - this means you go have gone now and again to get your teeth checked, but not every year. ☐ Do you only go **when you have trouble** with your teeth? - for example if you have toothache. ☐ Do you never go to the dentist?
	**Q14. Is it difficult for you to get appointments to see the dentist for routine care?** This is talking about normal appointments to check your teeth or get fillings. This is not talking about emergency appointments when you have trouble with your teeth.
  	**Q15. This question is about what makes it difficult to get your teeth looked after by a dentist** There are lots of reasons why people find it difficult. Please tick ☑ the reasons that are true for you. You can tick more than one answer: ☐ I'm scared of dentists / treatment on my teeth ☐ I don't have time / the surgery isn't open at the right times

☐ I can't get to the dentists

☐ There isn't a dentist near where I live

☐ The dentists are all full and won't take me

☐ The dentists only help people who can pay for it

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

☐ I don't know

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

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

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

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

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

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

You can tick more than one answer:

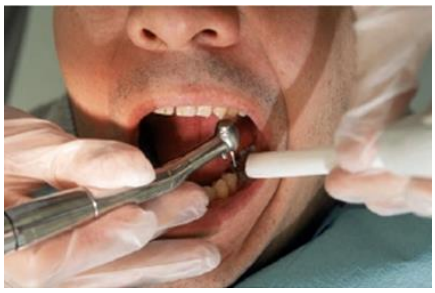
☐ No-one

☐ Accident and Emergency

☐ Doctor

☐ Pharmacist

☐ Someone else (please tell us who in the box)



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

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

☐ I <u>would</u> need treatment = Yes, the dentist would have to make them better

☐ I <u>would not</u> need treatment = No, my teeth are fine

☐ Don't know

Q20. Is there anything else you want to say?

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

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

Please tick ☑ the right box for you.

Thank you for helping us

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

We will not tell anyone what you have said.