Hearing problems in the learning disability population: is anybody listening?

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easy read summary

people with learning disability tend to have more hearing problems than other people.

- often these hearing problems are not picked up by doctors, nurses, carers or even by the people themselves.
- living with undetected hearing loss means people miss out on information, social opportunities and entertainment.
- routine screening for hearing loss would improve the lives of many people with learning disability.

Summary
We undertook this project because we believed that hearing loss experienced by the target population was greater than the referral figures suggested. Therefore, we set up a trial service initiative designed to examine the efficacy of different referral routes into audiology services for adults with learning disability. This retrospective analysis focuses on the generation of data on hearing loss on a small population sample (n = 136) gathered over a 6-month period in 2012. We suggest remedial action now to prevent more problems in the future

There is increasing evidence from a variety of sources that people living with learning disability suffer disproportionately from health problems and are more susceptible to a range of illnesses and disease processes than is seen in the general population (Cooper et al, 2004; Emerson and Baines, 2010). It is also apparent that their health needs are greater and more frequently unmet (Jansen et al. 2004; Kerr et al. 2003). Hild et al. (2008) suggest that this may be because 'the knowledge of the carers regarding the medical history and the possible health problems of the individuals they are caring for are often insufficient' (2008:2).

Valuing People (DH 2001) noted that the population would have more associated health problems, including sensory impairments, and that this would require 'a greater level of health care support than is usually available from a primary health care team' (100:2001). Later, in Valuing People Now (DH 2009), the commitment to healthcare was made explicit. 'Key issues for the NHS are to achieve full inclusion of people with a learning disabilities in mainstream work, to reduce health inequalities and to ensure high quality specialist health services where these are needed' (2009:9).
However, behind the rhetoric, it is apparent that the 'high quality specialist health services' are not meeting the needs of the population. This is particularly evident in the case of sensory impairment which is often overlooked or simply not recognised in adults with learning disability (Baxter et al., 2006:95). When this is the case appropriate assessment and management of the problem is not offered. This in turn results in prolonged difficulties for the individual with the potential for more serious clinical repercussions in later life.

As explained by HaLD (Hearing and Learning Disabilities (HaLD) 'their learning disability precludes them from receiving adequate support for their hearing problem and the failure to address their hearing loss will in turn exacerbate the effects of their learning disability' (www. hald.org.uk).

We can only speculate as to why this may be. Clinicians, for example, may attribute lower levels of intellectual and social functioning to the person with learning disability (McCulloch et al. 1996; Lavis et al. 1997; Yates, 1995). This means they may be less likely to offer screening or assessment or to prescribe treatment routinely offered to the majority of the population. This is an example of 'diagnostic overshadowing' by which clinicians unintentionally focus on the background of learning disability to explain the presence of more immediate health problems (Mason & Scior 2004). Not offering screening or testing and so depriving people of the potential benefit from aids or adaptations leads to even more difficulties for people with already poor communication skills, which in turn exacerbates their presenting condition and reduces overall quality of life (Mondelli & de Souza, 2012; Ciorba et al. 2012). This introduces a human rights angle to healthcare, which, although it goes beyond our remit here, needs to be acknowledged.

Knowledge context

The topic of hearing loss in this population and has attracted attention for some time (Balkany et al., 1979; Roizen & Patterson 2003). The prevalence of hearing loss is estimated at between 30% and 40% (Carvill 2001; Meuwese-Jongejeugd et al. 2006). These figures account for individuals with hearing loss associated both with their syndromes or associated condition (where present) and also those with more generalised or idiopathic learning disability. The difficulty of testing in this population is noted by Miller and Kiani (2008) who say 'debilitating co-morbidity remains largely undetected by carers and professionals due to presence of additional disabilities and complex clinical presentation in this population on the one hand, and lack of specialist hearing impairment service provision and difficulty in accessing generic audiology services on the other hand' (2008;26).

This should be considered alongside findings from studies which used samples from the general population. Here, investigations to calculate the levels of hearing loss (defined as a loss of 25 dB +, averaged over frequencies 500, 1000, 2000 and 4000 Hz) were carried out in Australia and Italy. They found prevalence rates of between 16% and 17% (Quaranta et al. 1996; Wilson et al. 1999). Kerr et al. (2003) in their study found that of almost 500 participants with learning disability who participated fully in the screening tests, 361, or just over 70%, were thought to have satisfactory hearing by their carers. After testing, the actual figure was shown to be just 11%. The rest were living with varying degrees of undetected hearing loss described as from mild to profound (2003:139). And in a large longitudinal study of almost 10 000 people, Herer (2012) discovered a 24% rate of hearing loss in the learning disability population which equates to a rate of 1.4 times higher than in an equivalent general population (age 18–55 years).

Within the learning disability population, there are a large number of syndromes that present with a co-morbidity of learning disabilities and hearing loss. However, of these, Down syndrome is associated s with the highest prevalence of hearing loss (Roizen & Patterson 2003; Shott et al. 2001). Figures for this cohort suggest that they are particularly exposed to early onset of age-related hearing loss (Buchanan 1990; Evenhuis et al. 1997).

One response to this difficulty in accessing the population is to introduce screening. Health screening, in general terms, needs to be contextualised, and this is usually done within the framework of a cost-benefit analysis (Uus et al. 2006). To be adopted as policy, any screening programme needs to fulfil four main criteria based on Wilson & Junger (1968) earlier and definitive work. More recent information is available from the UK National Screening Committee (2012) who state that:

- the impact of the condition being screened for needs to be well understood.
- the condition needs to be of sufficient clinical concern to warrant the attention.
- effective and available interventions need to be in place.

● alternative access to therapy/treatment (e.g. self-referral) is not widely available.

Smith et al. (2000) were clear about the desirability of screening for this population when they said 'All people with learning disabilities should be tested shortly after birth, then receive educational audiology input during schooling through screening mechanisms until leaving children's services. It appears that a large proportion of those with learning disabilities have an undiagnosed hearing loss when they enter adult services. Routine testing on transfer to adult services may be necessary and in those with Down's syndrome, again in middle age to detect early presbycusis' (2000:940).

Local context

In Sheffield, the Case Register has details of 3084 adults with learning disability in the city (figures from June 2009). This equates to roughly six per thousand of the population which is broadly equivalent with the national figures described by Emerson et al. (2011). The diagnostic criteria used by the Case Register are based on the national strategy 'Valuing People' (DH 2001) where learning disability is defined by - the presence of a significantly reduced ability to understand new or complex information and learn new skills, along with a reduced ability to cope independently, which started before adulthood, with a lasting effect on development (2001:14). The Register uses additional criteria, including use of learning disability services and Statement of Educational Need by reason of learning disability.
The raw data is further categorised into diagnostic subsets. Our focus, as outlined below, was specific to one of these subsets and so we were interested in the calculation of a population of 213 people locally with Down syndrome.
Audiology services have, at the time of this study, contact with 60 of these people (approximately 28% of that group) who are recorded as having a hearing loss of some kind. There are therefore around 150 people (or approximately 70% of that population) living with potentially undiagnosed hearing loss.

Aims and objectives

The overall aim of the initiative was to estimate the levels of undetected hearing loss in the local population with learning disabilty with a view to increasing access to Audiology Services. We did this by undertaking a comparison of three different paths to referral which are described in more detail below. More specifically, and to make the project more manageable, we wanted to target two cohorts of this population: people with Down syndrome and people living in residential accommodation as both groups are known to have higher needs when accessing audiology services (Evenhuis et al. 1997). To achieve this, the objectives were then to:

● design a questionnaire to capture information about ear health and hearing problems in this population and to highlight this issue for target families

● deliver/pilot the questionnaire to a sample of this population and to their families and carers provide a report locally on findings from questionnaire and feedback to the Improving Health Group

● based on the above, to design and implement a care pathway that would assist professionals to better care for the hearing impairments they come across in their caseloads

● compare number of people who were happy to have their hearing assessed when offered a hearing assessment via the different initiatives

● compare the incidence of hearing loss within groups of individuals with learning disabilities to provide an indication of the sensitivity of the initiatives attempted.

Methods and processes

For this to happen, we had to undertake some initial groundwork to assess the current state of hearing health in the target population. This was done as part of the normal service delivery to the client group. Input from our academic colleague was after the event and focused on analysis of data, the knowledge context and writing the interim report. As such, and after consultation with the relevant faculty personnel, no ethical permissions were deemed necessary beyond an acknowledgement of confidentiality.
There were three strands to our approach. We went directly to a purposive sample of residential care homes where we knew there would be individuals likely to have some hearing loss; we delivered a questionnaire to families and individuals with Down syndrome to prompt referral, and we monitored the regular referral routes into audiology services.

Residential care homes

With our reading of the literature (Jansen et al. 2004) and from our local knowledge, we were aware that this client group might be more susceptible to living with undetected hearing loss. The initiative of offering hearing tests to multiple residents within a single residence was offered to four residences where the authors had regular contact and were able to reach agreement for these hearing tests. There was no reason for selecting these residences based on the demographic or health issues of the residents. Hearing tests were then offered at the residences. Over a period between September 2012 and December 2012, a total of 38 individuals were assessed. We discuss the actual process in more detail below. The breakdown of numbers for the residential care homes appears in Table 1.

The questionnaire

A questionnaire was designed by the fieldworker, using principles of Easy Read. This was then delivered as a mail shot to the families of individuals with DS (see Appendix S1).

table 1 about here

The questionnaire was employed to identify risk factors associated with hearing loss, which would elicit a referral for diagnostic assessment. The results presented are not those of the questionnaire itself, but of the subsequent hearing assessment, which were prompted by the questionnaire and then carried out in the Audiology clinic.
The questionnaire asked the individuals to provide information on their own (and/or their families') perception of their hearing. In addition, we wanted to find out whether the questionnaire was useful as a means of eliciting information within the broader goals of the project to examine referral routes. Of the 207 questionnaires delivered, we received 74 responses. But of these, only 22 took up the offered option of an appointment at the clinic.

It is on the 22 that we base our figures which are displayed in Table 2. Even a cursory glance at the figures confirms that the questionnaire has prompted a worthwhile response as of the above; there were ten individuals whose hearing was loss sufficient to warrant amplification at this stage.

Regular referral routes

In addition to our planned interventions, we continued to receive referrals via the usual routes. Typically people are referred by their GP or through contact with the community Learning Disability team and while we were visiting residential homes and collating information from the questionnaire a series of referrals continued. The numbers are displayed in Table 3. Again, the numbers reveal the value of maintaining referrals via these routes. And it may be that this can be used to support an argument for an extension of the annual health check as a necessary part of an overall screening process (Felce et al. 2008; Robertson et al. 2011).

Findings

The overall numbers (see Table 4) demonstrate convincingly that the undetected hearing loss in this population sample is substantial, being very nearly half of the total assessed. It must also be noted that the actual figure may yet prove to be higher as the numbers for those with as yet unconfirmed hearing status could rise as some individuals need more than one appointment to arrive at a conclusive result.

The most striking results occur in the survey of individuals with DS. All but one was identified with some hearing loss. In the case of the individual for whom a hearing loss has not been identified, their hearing has not yet been assessed due to nonattendance, so a hearing loss has not been ruled out. In the residential category almost half of the sample had hearing loss and of those nearly all would benefit from some hearing aid. In the routine referrals, the GPs and the community Learning Disability team picked up over half of the referrals and of these over a quarter had hearing loss on testing.

Looking at the sample as a whole, even for those whose hearing is currently assessed as satisfactory, the ageing process may reduce this to a point where further assessment and hearing aids become necessary. For those who are assessed as having hearing loss that warrants a hearing aid, the outcome is not necessarily guaranteed to improve their hearing (see Knudsen below).

Carrying out this work with individuals with learning disability brings its own challenges. For example, the testing carried out depended on the capacity of the person whose hearing was being assessed. Location also has an effect on testing. In the client's own home, Otoscopy, OAEs (OtoA- cousticEmissions) and Audiometry were attempted. These test methods are briefly described below. If these tests did not suggest that hearing was satisfactory or that the responses were insufficiently reliable to draw conclusions regarding the client's hearing, further testing would be offered within a clinical setting.

tables 2,3, 4 about here

Otoscopy

Observation of the pinna, external auditory meatus (ear canal) and tympanic membrance (eardrum). This type of testing was used to provide some information on ear health, for example, presence of an active infection in the external part of the ear or presence of cerumen (earwax) that may be sufficient to affect the accuracy of a hearing assessment.

OtoAcoustic emissions

The recording of OtoAcoustic Emissions can be used as a screening or diagnostic tool to evaluate the outer hair cells of the cochlea. A small soft probe is placed in the client's ear

and a quiet clicking sound presented. The normal hearing cochlea will generate a sound in response. This response can then be detected using a microphone. This test's duration is typically around 2 minutes per ear, and requires a client to remain relatively still and quiet. No further participation from the client is required.

Modified pure tone audiometry

The client is asked to perform a specific action in hearing the test sound, for example, placing a peg in a basket or raising a hand. This testing requires the skills to carry out an action as the client intends and also to wait. The British Society of Audiometry Recommended Procedure for Pure-tone Air- conduction and Bone-conduction Threshold Audiometry With and Without Masking (2011) was used as far as possible with modifications appropriate to each individual client. These modifications included longer presentation of stimuli, larger gaps between presentation intensities and frequent encouragement to the client.

As mentioned above further, more complex test are sometimes required which need to be carried out within a clinical environment. The CERA (Cortical Evoked Response Audiometry) is such a test. It is an electrophysiological test of hearing which involves electrodes secured onto the client's head, and sounds presented through headphones. The electrical signal from the auditory nerve in response to the sounds would then be detected, if present, and evaluated by the tester to give an estimation of threshold. This test duration is typically 15 min per ear and requires a client to remain relatively still, quiet and alert. No further participation from the client is required.

This testing was carried out at the Sheffield Hearing and Learning Impairment Service by a Clinical Scientist in Audiology who specialises in hearing assessment of adults with learning disabilities.

Satisfactory hearing in this instance was defined as either having Otoacoustic emissions in a minimum of 2 frequency bands of ≥6 dB or, if hearing thresholds could be measured, thresholds of ≤25 dBHL at a minimum of two frequencies.

Discussion

Our study has highlighted some of the challenges that accompany delivering audiology services to this population. Even within our own auspices and with the benefit of a comprehensive database, we still managed to find individuals whose hearing justified further treatment and/or testing.

There are other issues too raised by our findings. Of those people, we contacted the number living in residential care who were identified as having hearing loss was just over half of this subset of the population. And of those, nearly all had hearing loss of an extent that might be improved with a hearing aid (see Table 1). This invites questions on the role of care staff in assessing the hearing of their client group. It may be that the phenomenon noted in relation to family carers, whereby neither the affected individuals nor their family members are aware of any hearing loss, is replicated in residential care homes.

This in turn poses a question on the use of and access to referral routes. This was core to our study. In Table three, we can see that the Community Learning Disability Team leads in terms of the number of referrals made. But equally importantly, the numbers of people they refer with previously undiagnosed hearing status is also much higher than we find from other sources. This may indicate that a targeted screening programme aimed at those with well-established co-morbidities of hearing loss and learning disabilities such as Down's Syndrome and also clients in residential care may be very effective in identifying previously

undiagnosed hearing loss. The high incidence of hearing loss found in this initiative certainly suggests that larger study looking at the sensitivity and specificity of a targeted hearing screening programme for adults with learning disabilities is justified.
Apart from the prevalence, the severity of hearing loss also appears to be increased in adults with learning disability. In the general population, mild hearing loss, defined as losses of 25–45 dB (12.2–13.8%) is about four times more frequent than moderate to profound hearing loss (2.8–4.0%) (Davis 1989). In the adult population with learning disabilities, the distribution is equal (14.9% and 14.5% respectively). This also applies to subpopulations with Down's syndrome (31.1% and 26.0%, respectively), and with learning disabilities by different causes (11.2% and 11.8%, respectively). It is not very likely that the entire difference is explained by our inclusion of losses of 41–45 dB into the class of moderate hearing loss (Quaranta et al. 1996; Wilson et al. 1999).
The high level of hearing loss displayed in this relatively small sample is, if the numbers can be extrapolated to the overall population, a big concern. To be fully aware of the scope of the problem, services must engage with practitioners and users of services in a systematic fashion to know in detail the extent of hearing loss experienced by the local population. One way to approach this would be to organise screening programmes.
However, even if screening were to be successfully adopted and the full extent of the audiological needs of the population with learning difficulty could be quantified, this would not of itself improve the hearing of all of those individual identified as living with hearing loss. For some, the hearing loss might be of a degree and complexity that would not be amenable to improvement by hearing aid. In addition, there is often a negative impact that long-standing and unidentified hearing loss can have on the auditory system that can reduce the benefit of amplification.
Even when a hearing aid is a possibility, and for half of our total population, this was the case, it may be that, as in the general population, the uptake and use of hearing aids is not good (McCormack & Fortnum 2013). Knudsen et al. (2010) conducted a review of the international literature and were able to state in the introduction that 'Despite the large prevalence of hearing impairment in human populations, the uptake of hearing aids is still poor' (2010; 127). In their conclusion, they claim to have found that 'self-reported auditory difficulty is highly important in aural rehabilitation, possibly more important than objective hearing sensitivity, which showed less consistent effects on outcomes' (2010; 144). This has direct relevance to our population as it is shown to be very unlikely that individuals with learning disability themselves or their carers will be aware on any hearing difficulties. This, we argue, makes the need for specialist services even more urgent.

Limitations

Any small-scale pilot study is necessarily limited, but the findings are so congruent with what is generally known that we have confidence in the transferability of the findings to larger populations. And the relatively small size of the sample in no way reduces the urgency of the situation for those identified with undetected hearing loss.

Conclusions and implications for policy and practice

Our findings confirm that undetected hearing loss is prevalent in this population. There is also evidence that the population is increasing, and work done locally suggests that the biggest rise is in that cohort with profound and multiple disability (Parrot et al. 2008). This is precisely where we would expect to see more individuals with hearing problems. The situation is therefore destined to escalate making remedial action now a necessity to forestall a proliferation of hearing problems in the future. The Annual Health Check relies on information from carers as well as the individual with ID. As has been seen, they may be unreliable witnesses to the presence of hearing loss. It could be argued that by not providing

a more proactive service, the annual health check fails to meet the standards required highlighted by Turner & Robinson (2011).
Lennox et al. (2007) found that health checks improved the detection of hearing loss while Chauhan et al. (2010) concluded their study by saying that a more targeted approach, which included an assessment of hearing 'might be more appropriate in primary care for improving care for people with ID than an extensive ID health check' (2010; 485). All of this suggests that specialist services remain vital to the wellbeing of people with learning disabilities who remain susceptible to hearing problems. Our next step is to look for funding to conduct a regional study before going on to develop a national referral pathway.

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