



# The Uphill Struggle: services for Deaf and hard of hearing people—issues of equality, participation and access

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**ABSTRACT** *This article focuses upon the ways in which Deaf [1] and hard of hearing people are excluded from participation in society. In particular, the focus is upon the ordinary expectations that members of society have in terms of participating as citizens and performing socially sanctioned, adult roles. The roles of ‘citizen’, ‘employee’, ‘parent’ and ‘patient’ are discussed. The data illustrate how the organisation and delivery of services can undermine, rather than facilitate, the performance of these roles. Despite policy emphasis on social inclusion, current services and legislation fail to provide a firm basis for the full participation of Deaf and hard of hearing people in British society.*

## Introduction

Service provision for Deaf and hard of hearing people is a neglected area of research and development, although authors and commentators have repeatedly and successively highlighted issues of access and linguistic barriers as central areas of importance (Lane, 1995; Jones *et al.*, 2001). The two groups highlighted in this article are located at different ends of Lane’s (1995) ‘constructions of Deafness’; with Deaf service users being placed firmly within the ‘linguistic minority’ construction and hard of hearing service users falling within the ‘disability construction of deafness’ (Lane, 1995). As such, the groups have widely varying service requirements and only rarely does or should provision overlap. For legislative and social policy purposes, deaf people are categorised as disabled, although there is considerable disagreement within the Deaf community and amongst commentators as to whether

or not (and in what circumstances) deafness should be regarded as a disability (cf Finkelstein, 1991; Harris, 1995a; Lane, 1995). There are also debates concerning the extent to which Deaf people, as a linguistic minority using British Sign Language (BSL), share more common features with minority ethnic groups than they do with other groups of disabled people (Lane, 1995).

## **Background**

Deaf and hard of hearing people have widely different experiences of the social world, and access to service provision should reflect and respect these differences. Deaf people generally subscribe to conceptions of Deaf culture, which they claim is both generated and promulgated through use of BSL (Padden, 1991) and there is no concurrent movement within the heterogeneous hard of hearing group. Very little attention has been paid to issues of access to services for Deaf people. One exception is the work of Jones *et al.* (2001) reported in this journal which focused on the service requirements of Asian Deaf young people.

Social work services for Deaf people were traditionally provided under the 'missionary' framework, since in its infancy this service commenced in church missions (Parratt, 1995). Recent developments have moved away from both the paternalism and dependency-creation of this framework towards a modern service, which questions its roles and responsibilities in relation to Deaf service users. In particular, one of the first tasks of the National Council of Social Workers with Deaf People (NCSWDP), created in the late twentieth century, was to attempt to differentiate the roles of social worker and BSL interpreter.

Hard of hearing people are likely to use residual hearing, amplification technology and lip-reading within everyday interaction. It is generally unusual for hard of hearing people to learn BSL, and this lack of a shared linguistic past and future contributes to their relative lack of group coherence in terms of political solidarity and lobbying potential. In terms of both services and issues of identity, hard of hearing people are far more likely to subscribe to what Lane refers to as the 'disability construction of deafness'. The hard of hearing group is not homogenous (Morgan-Jones, 2001), but contains many people who have acquired hearing loss from a variety of causes. Estimates of the hard of hearing population size put it at around 10 million (Jones *et al.*, 1988), making it very much larger than the Deaf group at 50,000 [Royal National Institute for the Deaf (RNID), 2000a]. Generally, the hard of hearing group is much less well understood in terms of service requirements. Indeed, rudimentary 'Best Practice Standards' (RNID, 1999) for social services personnel working with both groups have only recently been agreed, and it is unclear to date how these will or, indeed, can influence service provision.

## **The Study**

The research was conducted using focus groups to explore the desired outcomes of social care, and ways of collecting and using information on outcomes (Bamford *et al.*, 1999). Separate focus groups were held with Deaf and hard of hearing partici-

pants. The secretary of a local Deaf Society assisted in recruiting Deaf participants. Subsequently, nine Deaf people attended a series of three focus groups at the Deaf Society. The meetings were facilitated by one of the authors and a Deaf external consultant. Two Deaf transcribers provided a written record for the external consultant and two interpreters interpreted the interaction and produced a voice-over that was subsequently transcribed and compared with the written transcript produced by the transcribers. The main topic addressed was the identification of outcomes and the best means of collecting feedback on services on a regular basis. The participants varied in terms of their gender, age (range twenties to sixties), educational background, employment, marital status, and whether or not they had children.

People who were hard of hearing were recruited in two ways. The specialist social worker for Deaf people provided an anonymised list of service users who used lip reading, residual hearing and hearing aids, and who did not identify as Deaf. A letter of invitation to participate was forwarded to a sample of these users by the Social Services department offering either group discussion or an individual interview. Of the 12 people contacted, five expressed an interest and four eventually participated. In view of the low numbers of people recruited by this method, staff at a resource centre for deafened people agreed to identify additional participants. Two further people were contacted making a total of six hard of hearing participants. Two focus groups were subsequently held. The meetings were attended by two note-takers who produced a written record so participants could choose to read the notes, when they wanted a break from lip reading. A lip speaker attended one of the meetings. Five participants attended both meetings and one person chose an individual interview. All but one of the participants was female, and all were aged between 30 and 50. Employment and marital status varied and all married participants had hearing partners. Four participants were parents, half of whom had preschool children.

The research that forms the basis for the findings below has been analysed from a social model perspective (Oliver, 1990).

### *Citizenship*

Both groups wanted to participate in typical activities of everyday life in ways that maximised choice and control. They identified a range of barriers which either proved exclusionary or limiting in terms of practicing effective citizenship including, being able to make informed choices; being treated equitably with hearing people, and with other Deaf and hard of hearing people and being able to make a contribution to society.

The Deaf group identified 'access' as a major concern. In a general sense for Deaf people 'access to information' is a continual and recurring problem (Harris, 1995a,b), which goes far deeper than the evident problems caused by a lack of sufficiently skilled interpreters (Harris, 1997). Although many laypersons consider that technology can 'solve' many of the problems that deafness presents, this forms a 'naive solution' in situations where the technology is missing, unaffordable or

unusable owing to lack of training. The Deaf people in this study experienced difficulties in acquiring equipment (fax machines, pagers, minicomms, etc.), in obtaining information on available payments for the latter and also in obtaining training in their use (for example, how to use the Typetalk service).

For Deaf people, information and its provision may effect social inclusion or exclusion at both local and national levels. There is currently an acute shortage of trained sign language interpreters in the UK. Estimates range from 100 qualified and 300 trainees (RNID, 2000a) to 117 registered qualified and 228 registered trainees (British Deaf Association, 2000). Whatever way you approach this issue, when we consider that there are estimated to be between 50,000 and 70,000 Deaf people for whom BSL is a first language (RNID, 2000a) there is a vast deficit in numbers of available appropriately qualified interpreters—representing a consequent shortfall in access to information for those wishing to use such services. The effect that this shortfall has on facilitating social inclusion or exclusion is self-evident:

*The problem with the interpreting service is that when we are trying to book an interpreter a lot of these people are working in colleges and, of course, in term time, they're fully booked and we can't get the person we need and what we are really saying is that we're lumbered with people with Stage 1. [2]*

There was also evidence that a well-intentioned local initiative to improve communication access for Deaf people failed to live up to expectations. During the study period, the local council provided BSL training for their reception staff, but Deaf people who attempted to use this facility discovered that the staff had only received a very basic 10-week course and their skills were consequently extremely limited. In effect, an initiative that was designed to effect social inclusion, by facilitating Deaf consumers' access to council staff, resulted in social exclusion, since the strategy failed to consider the realities of time and training necessary to undertake competent sign language interpretation.

Both groups repeatedly returned to the theme of equity. They wanted to be treated equitably with hearing people, with disabled people, and with other Deaf and hard of hearing people. Interestingly, both groups considered that services were designed more specifically to meet the requirements of the other. Hard of hearing people and deafened people used a local resource centre for equipment provision, but the Deaf group took a principled stance on this centre:

*We don't actually try to use the resource centre. There is a communication problem up there because they don't use sign language and we have to write things down. That's not actually the way we want to operate.*

The Deaf group considered that there was no equity or sense of equivalence, since they were unable to access equipment and information that was available to the hard of hearing group. Conversely, some hard of hearing participants considered that the specialist social work service was focused more on Deaf people. Consequently, both groups harboured feelings of unfairness and inequity.

Perceived inequalities between participants were fuelled by the lack of transparency over the equipment available and eligibility criteria. Both groups complained of

'rationing' operated by Social Services—for example, 'not letting on' that pagers were available and, in some places, apparently restricting services to only 'profoundly Deaf service users'. Further inequities resulted from the use of different equipment sources, with some people finding that the hospital audiology service provided easier access to equipment than social services. Reliance upon charities for the provision of essential equipment was obviously unacceptable and, again, could result in inequalities. Even where equipment was provided by social services (for example, a loop system), some people found they had to collect it or face a considerable delay. A picture emerged of patchy, piecemeal service provision and inadequate information on available equipment that relied largely upon 'grapevine knowledge'.

Although Deaf people in the study were assertive in relation to requests for technology (pagers and compact minicomms) for use in the home, they frequently felt thwarted by Social Services over the issue of payment for these items. In these circumstances, they faced either paying for the item themselves, or applying over and over again. In response, they became adept at 'badgering' Social Services staff—sometimes over a period of years.

Both groups described their participation in a range of community groups including disabled people's groups, Parent Teacher Associations, playgroups and local authority consultations. A range of barriers to full participation in such groups was identified and some participants had withdrawn due to the difficulties they experienced. The lack of deaf awareness and apparent lack of resources for providing communication support were the main barriers to participation. One mother who was hard of hearing, for example, found it difficult to help effectively at a playgroup because of the problems in lip-reading other people's children, particularly when they were upset. However, she had not discussed the possibility of funding for a lip speaker either from the playgroup or the local Social Services department, but she was in the process of applying for Disability Living Allowance (DLA) and intended, if successful, to use the money for this purpose.

Lack of clarity over local funding policies in relation to BSL interpretation sometimes resulted in the exclusion of Deaf people at the local level:

*In the past I have looked in the newspaper and I've seen there's been a meeting in [the city] and I've thought, 'Oh I'd like to go to that', but I have a problem because I can't get an interpreter ... if I contacted an interpreter and said 'Please could you come with me' the question would be who is going to pay, because I can't pay.*

Many group members wished to contribute to society in a general sense and claimed to have valuable experience that was not currently used. In particular, they thought they could have a valuable role in increasing awareness, and providing training for staff in social services and schools. One Deaf parent felt his experience as a parent might be useful to hearing parents with deaf children:

*If anybody asked me for help I would support them ... I'm Deaf, I grew up all*

*right, I've got a job, I can communicate, I've got oral skills, I can write, but nobody ever asks me for any help.*

Taken as a whole, the evidence shows that the participants in the study are unsupported in their efforts to exercise their rights of citizenship and that, consequently, injustice and hardship occur.

### *Employment*

Study participants, in common with the general public, had widely varying experiences in employment. While some employers were supportive and open to the provision of assistive equipment, others saw it as a problem for the individual employee to resolve:

*I'm very lucky because of equal opportunities. Even if I was the lowest scale in my job ... they would bend over backwards ... They're very good I must say, I can't complain.*

*They didn't do anything to help. I asked for an amplified phone, they didn't give me that. They were just no help at all really ... 'if you want it, you get it yourself' type of attitude.*

Several problems were identified with the Placement, Assessment and Counselling Teams (PACT), responsible for provision of work-related equipment. Not all local employers were aware of PACT, and Deaf and hard of hearing employees were not routinely referred to the service for assessment. Some employees were reluctant to use the service:

*I am the only deaf person who works here as far as I know. I don't want to make myself unpopular by making demands and drawing attention to my problem.*

There was a generalized lack of knowledge of the range of equipment available. One hard of hearing participant had been supplied with a meeting pack, which incorporated two microphones, a loop and a folder for note-taking, which assisted participation in meetings. This equipment would have been of use to another participant, but as she was not aware it was available, she had withdrawn from attending meetings.

Deaf participants expressed mixed opinions about the extent to which the introduction of Disability Living Allowance (DLA) had proved assistive to their employment. Many had found the application process very difficult. Those who had been successful had only achieved this after a considerable period of applying and reapplying. There was also a range of opinions on the 'correct' use of DLA. While some participants were adamant that DLA should be used as a 'compensatory mechanism'—to pay for the facilitation of access to information that hearing people take for granted (such as the provision of information via interpreters and technology)—others argued that it should be used to compensate in a more structural sense for lower incomes and lack of job opportunities, and that funding for interpreters and technology should be provided *in addition* to DLA.

Hard of hearing people are much less likely to be eligible for DLA at even low levels (RNID, 2000b). Several participants used the Typetalk service at work. Access to other items tended to be 'hit and miss'. This group shared with the Deaf participants the experience of repeatedly requesting items such as amplified phones and being told to 'get it yourself'. One participant claimed that the technological solution supplied by PACT proved inappropriate:

*I've had pagers and all my colleagues, sat at desks had a pager on their desk and I wore one. If they wanted my attention, instead of throwing paper clips they used to just press this thing and it used to vibrate, but it used to give me a heart attack nearly every time because it was such a strong vibration, or if I used to have it on my desk the whole desk would rattle ... So I gave it back and I also asked them if they could swap the minicom, for a uniphone because my colleagues are hearing. And it was just gonna be easier to use that. But they wouldn't do it that way, they said you can give the stuff back, but your employer still has to find £300.*

Overall, the picture was one of a lack of flexibility in service provision for hard of hearing people and that, far from the vision contained in *Modernising Social Services* (Stationery Office, 1998), provision is still service-led, rather than needs-led.

### *Parenting*

In our study, parents of babies and young children emphasised the importance of equipment to alert them to their baby crying. These parents were frustrated by the lack of understanding among specialist workers. One Deaf parent whose vibrating pager had broken, for example, was advised to replace it with a standard baby alarm with flashing lights. While this device might have been of use during the day, it was not during the night when she was asleep. Parents also expressed concern that social services staff did not appreciate the urgency of repairs to essential items of equipment such as pagers which alerted them not only to the baby crying, but also to the telephone, doorbell and car alarm:

*I had to take myself down there because it was urgent and get it. I wasn't going to wait for Social Services to get me one because it was important that I have it, especially where the children are concerned, to hear them at night (my husband works shifts).*

Parents of school age children encountered access issues when they wished to participate in school events such as concerts or parents' evenings. One Deaf couple routinely approached the school for funding for an interpreter, but other Deaf parents were less assertive and unaware that they might be eligible. Since all of the hard of hearing parents had hearing partners, they used a combination of residual hearing, lip reading and their partners. This was far from ideal, however, and some parents reported feeling marginalised and excluded from the discussions. One hard of hearing mother stated:

*I've got [daughter's] first nativity play tonight ... and I'm quite nervous and*

*hoping that I'll get there, get the front seat. I don't want to say to the teacher 'Could I have the seat at the front?' ... So I'm quite nervous and hoping that I will pick up something from that, because to me the first one's quite important.*

The tension between the Social Services role of supporting parents and protecting children has been highlighted previously (Wates, 1997; Goodinge, 2000). Most participants expressed concern over these conflicting roles, and it was clear that anxiety over child protection issues was a barrier to seeking support with parenting. In discussing a fictitious vignette describing a family with social problems, Deaf participants expressed reluctance to involve Social Services:

*Our view is that if Social Services get involved, the situation could actually be worsened by that. This is our view from history ... that is why we back off.*

Similar concerns were expressed by hard of hearing participants. While one parent recognized the need for counselling and deaf awareness training for her daughter, she was reluctant to seek such help from Social Services. Another participant stated:

*He [husband] can't understand why I need to come here, why we need the social services, because we haven't got a problem. I said 'It's not a problem, it's such as equipment'. He's found it very hard, (he says) 'we don't need a social worker', I say 'Look ... it's not the social worker as such that we need, (like) we're having a family problem, it's equipment that I'm after'. He has a lot of difficulty accepting it.*

The local Social Services department recognised that supporting 'disabled parents' (within which group they included Deaf and hard of hearing parents for their purposes) was a relatively neglected area. As in many other departments, there was no designated budget for this purpose, either within Adult Services, or the Children and Families team. The paucity of current provision has been highlighted by a recent Social Services Inspection of support services (Goodinge, 2000), and this may stimulate future service developments.

Greater clarity over support services and the arrangements for funding BSL interpreters in everyday activities, such as preschool playgroups and school events, would facilitate service equity, and enable Deaf and hard of hearing parents to participate more meaningfully in the mainstream activities taken for granted by hearing parents.

### *Patient Rights*

In our study, both groups experienced problems in accessing and using health services. The Deaf group found their right to privacy consistently violated when Social Services were called upon to interpret for hospital appointments. Deaf participants were outraged that social services staff 'know what is wrong with us' and many considered that interpreters should have handled such situations. This situation has been known to both health and social service providers to be a consequence of the lack of sign language interpreters. Service users have to make the difficult choice between using social workers or doing without interpretation. This

issue has long been recognised by the National Council of Social Workers with Deaf People (NCSWDP). Indeed, in the evidence they presented to the Royal National Institute for Deaf people Commission of Enquiry into human aids to communication 10 years ago, it stated:

*Far too many agencies, voluntary and statutory, still rely, many believe appropriately, on social workers and social work assistants to act as 'Human Aids to Communication'. The vast majority of the membership of the NCSWDP believe that this expectation and reliance on the sign language communication skills of social workers is wholly inappropriate.* (Hope, 1991).

It appears likely that the lack of sign language interpreters was the root cause of this issue as, although complex and time-consuming as a procedure, 'profoundly deaf people' are generally considered eligible for DLA care component which would provide funds for sign language interpretation (RNID, 2000b)

The lack of Deaf awareness of hospital staff caused a number of problems. The importance of interpreters was not recognised and, instead, some relied on written communication, which led to frustration among Deaf participants:

*English needs translating to BSL because ... if you just write it down, there isn't any communication ... the hospital really must be trained to understand that.*

These issues of privacy and lack of signing skills affect the ways in which Deaf people can achieve or fail to achieve inclusion as patients of the health service. The following declaration in the Patient's Charter in relation to privacy seems in direct contradiction of the experience of our respondents:

*You can **expect** the NHS to respect your privacy, dignity and religious and cultural beliefs at all times and in all places.* (Department of Health, 1998)

However, a distinction is made between 'rights' and 'expectations' in the Patient's Charter:

**RIGHTS**—*which all patients will receive all the time; and*

**EXPECTATIONS**—*these are standards of service which the NHS is aiming to achieve. Exceptional circumstances may sometimes prevent these standards being met.* (Department of Health, 1998)

The issue of privacy as a right or expectation is a hollow promise when Deaf service users are faced with requesting interpretation from a social worker for a hospital appointment or manage without interpretation altogether. To date, the provisions of the Human Rights Act (such as Article 8) have not been tested in relation to routine violations of privacy. This Article states:

*Right to Respect for Private and Family Life: You have the right to respect for your private and family life, your home and your correspondence.* (Home Office Communication Directorate, 2000)

In relation to hard of hearing people's access to the NHS, again, rudimentary common sense would dictate that it is pointless to routinely operate systems that rely

upon shouting patients' names—especially in an audiology clinic, and yet this was found in the study. It was also apparent that hospital staff fail to adopt patterns of speech that render the conversation accessible for patients who lip-read and, in one case, made an inappropriate and offensive joke about the patient's hearing impairment. One hard of hearing participant clearly emphasised the lack of time for communicating:

*They haven't got time to slow down, they're rushed off their feet because they've got x amount of people to see. So they haven't got time to slow down for that extra few minutes.*

This comment was made by a woman whose child had died and displays a lack of professional care in a highly charged emotional situation. There is not even a notional regard paid to the principle of 'good will' that should apply in alternative communication scenarios (Harris, 1997).

Taken as a whole, these findings display a worrying lack of progress concerning the issue of patient confidentiality and conflict within the roles of social workers and BSL interpreters, and a failure to react flexibly and respectfully to patients.

## **Conclusions**

The evidence from this study is that significant barriers preclude the full participation of Deaf and hard of hearing people in performing the socially sanctioned adult roles of citizen, employee, parent and patient. In a social model sense, the participants in our studies have been further disabled by the manner in which services are provided and restrictions to eligibility. Health, social and employment services are not organised in ways that facilitate the inclusion of Deaf and hard of hearing people as full members of society.

Despite the current policy emphasis on social inclusion, current legislation and declarations of human rights appear to offer little leverage for improving services and, therefore, facilitating the inclusion of Deaf and hard of hearing people.

The study has shown that the services provided are not always appropriate in meeting the requirements of Deaf and hard of hearing people. These requirements are considered to be basic in nature; in other words, they form the basic minima for Deaf and hard of hearing people to participate in the activities of daily life, especially in their daily interaction with hearing people. As such, rights of citizenship extended to most areas of social and daily life for non-disabled people (such as those contained in the Citizens' charter, NHS patients' charter and the charter of Human Rights) appear to be routinely violated and yet it is difficult to comprehend how social services that are intended to ameliorate the effects of a disabling society should themselves present barriers to service user participation and social inclusion.

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## NOTES

- [1] The use of the term Deaf, with an upper case 'D' denotes those deaf persons who consider themselves to be a cultural and linguistic minority group, which uses sign language as its first or preferred language.
- [2] 'Stage 1' here is a reference to certificated levels in British Sign Language (BSL). The Council for the Advancement of Communications with Deaf People (CACDP) provides courses and examinations. As the quote suggests, stage 1 is very basic, typically requiring the candidate to attend an evening class for 10 weeks and pass a short test.

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