Living Options Partnership
Practice Briefing

Improving services for Deaf and partially Deaf people

Introduction

There are approximately 7.5 million people in the UK with some degree of hearing impairment. Of these, 50-55,000 are thought to use sign language.[1] It is worth acknowledging at this point the cultural complexity of the Deaf community. Many Deaf people have a culturally Deaf identity marked most noticeably by sign language as a common bond. Some Deaf people align themselves with the wider disability movement, but most see stronger parallels with the discrimination faced by other groups who share a common language such as minority ethnic groups. The experience and identity of people deafened in later life or with acquired hearing loss will be quite different.

This document builds on work carried out by a group of Deaf and partially Deaf people who were invited to share views and experiences of community care services. It highlights gaps in services and offers some practical suggestions for making services more responsive to the needs of the Deaf community.

It is aimed at purchasers and providers (both managers and practitioners) in health and social services. Although it focuses primarily on health and social services, this does not mean that these are the only, nor the most important, issues affecting Deaf people.

COMMUNICATION

Not surprisingly, problems with communication are central to Deaf and partially Deaf people's experience of services. Deaf people are often made to feel that it is their fault if they do not understand what is happening or being said. In general, services take little or no account of the varied communication needs of the Deaf community. It is often assumed and expected that Deaf people will have someone within the family to help them communicate, for example hearing children. It is also rarely appreciated that, for people whose first language is sign language, written information needs to be presented in a clear and simple way.

■ Action for change

- Ensure that Deaf people have access to interpreting services which can offer a range of communication support (e.g. British Sign Language (BSL), Sign Supporting English (SSE), Basic Sign Language for People with Learning Difficulties, lip speaking, deaf/blind interpreters).

- Ensure that information is made available in plain language, in pictorial form, or on signed video.
- Carry out an access audit: commission a Deaf consultant or Deaf people's organisation to assess how Deaf people's access to services could be improved.

INTERPRETING SERVICES

The lack of interpreting services is a major concern within the Deaf community. The report of the Commission of Enquiry into Human Aids to Communication raised a number of issues relating to the training and availability of communicators and interpreters.[2] The main problem is the lack of availability of interpreters. There are approximately 100 qualified sign language interpreters within the UK, serving about 50–100,000 Deaf people. The number of qualified lip speakers is also low. There are a number of Council for Advancement in Communication with Deaf People (CACDP) Stage II interpreters who do not have enough skills to give Deaf people the full range of services needed.

A number of social workers for Deaf people have a very basic Stage I level of signing skills, which is quite inadequate. Social workers sometimes act as interpreters for Deaf people at, for example, hospital appointments, meetings with solicitors, etc., and often their lack of specific skills results in Deaf people not fully understanding what is happening. There is a need for more social workers who are fully trained in BSL skills and for separate BSL interpreter provision for Deaf people. This would enable Deaf people to access a wider range of services and would offer them more opportunity for privacy in using the services available.

Some European countries, for example Finland and Sweden, operate voucher systems. These enable Deaf people to book their own interpreters for a variety of uses, such as visiting hospitals or going to college. A voucher system could offer Deaf people in the UK a great deal more freedom, giving them more choices and opportunities and enabling them to play a full and equal part in community life.

■ Action for change

- Ensure that social workers for Deaf people receive training in BSL to at least CACDP Stage II.
- Bring representatives from the Deaf community together to discuss whether a voucher system for interpreting services would best meet local need and, if so, how it might be resourced and implemented.
- Consider pooling resources between social services, health, housing and education services to fund an interpreting service.
- Explore ways of contracting with a local user-led organisation of Deaf people to run an interpreting service. If there is no existing organisation able to do this, consider what would be needed to establish one.

Independent living

Independent living is associated with the rapidly increasing numbers of people with physical impairments who are employing personal assistants to provide help with personal care as well as with domestic, social and employment activities. Although disabled people's individual needs may be different, the principles underlying independent living are equally applicable to the support services that Deaf people may require:

- control by users over choice of workers;
- flexibility and choice over hours worked and tasks performed;
- control by users over individual budgets.

Direct payments to individual users, user-controlled trusts to act as payment intermediaries, independent living advocacy schemes and personal assistance recruitment agencies are all responses to the growing demand for independent living packages which may be relevant to Deaf and partially Deaf people.

RESPONDING TO INDIVIDUAL NEED

The needs of Deaf people are as diverse as those of any other part of the community. Deaf people may be parents, they may come from Black or minority ethnic backgrounds, they may be lesbian or gay or they may be caring for elderly relatives. Community care assessments must adopt a genuinely needs-led approach and must consider the individual as a whole. For example, a partially Deaf wheelchair user who is also Jewish has a right to expect that a home care worker will respect her needs as a Jewish woman.

Services which place barriers in the way of users instead of helping them to achieve their goals (such as better health or an independent lifestyle) are disabling services. Needs-led service provision should aim to help Deaf people to identify and overcome the communication, attitudinal or organisational barriers which they encounter. It should not be concerned simply with providing a fixed range of services to people, based on assessments of the degree or nature of impairment.

Genuine needs-led services are, therefore, one practical outcome of an effective equalities policy. They are based on the principle that services must be equally available and equally appropriate to users, regardless of race, gender, sexual orientation, age, religion or class.

■ Action for change

- Recognise that, since the needs of Deaf and partially Deaf people vary widely and change with time, services should be tailored to meet individual need.
- Provide Deaf people with clear information on their rights to services and how to access them.
- Fund a drop-in centre where Deaf people can obtain information and advocacy.
- Involve Deaf and partially Deaf people in the training of care managers.
- Provide Deaf users with information on needs-led assessment in clear written form, in pictorial form or on video.
- Use and adapt the independent living model as a framework for needs-led service provision.
- Offer Deaf people delegated control over individual budgets to pay for whatever form of support or facilitation they may require, or to access independent living advisers.
- Offer Deaf people the opportunity to learn from existing PA users.

SOCIAL SERVICES

Many Deaf people feel that social services want to control them rather than enable or empower them. There is a need for more self-advocacy and the recognition that Deaf people have the right to make their own decisions about their lives and about the services they use.

Some social workers do not have adequate sign language skills and front-line staff need not only sign language but also Deaf awareness training. There is an overall feeling that social services departments have no real understanding of Deaf issues or Deaf culture. Deaf people's priorities are often not the same as those of social services. For instance, if an essential piece of equipment such as a minicom breaks down, then repair or replacement is a matter of urgency. Unfortunately, it is not always treated this way by those responsible for arranging supply.

Many social services departments do not seem adequately equipped to address the whole needs of families of Deaf people. For example, a Deaf man with two disabled children (who are not Deaf) is referred to a social services team with whose staff he cannot easily communicate. The team does not have any understanding of his needs as a Deaf person, and the result is often confusion and dissatisfaction. Similar problems exist regarding people with multiple impairments, for example Deaf people with physical impairments or Deaf people with learning difficulties. Any support that they might receive is usually fragmented between different services or different service personnel.

■ Action for change

- Provide Deaf awareness training (led by Deaf people) for all social services teams, not only sensory loss teams.

- Set targets for the active recruitment of more Deaf social workers.
- Commission a Deaf consultant or a group/organisation controlled by Deaf people to bring Deaf service users together with managers. The group could review the positive and negative aspects of the service and consider ways of improving it.

HEALTH ISSUES

For many Deaf people the experience of using health services has not been positive. The lack of awareness and training for front-line staff seems to be at the root of many problems. For example, one person reported that staff still called out names in a hospital waiting room, even after the Deaf person had informed them of their impairment. As a result, the individual missed their appointment. On another occasion, a Deaf person who went to the doctor with a sinus problem was told that they should not worry, as they were already Deaf. Deaf people often go to hospital for treatment and find themselves having to teach Deaf awareness to medical staff.

Interpreting is often either unavailable or inappropriate. For instance, interpreters may not see their role as purely one of facilitating communication. In some cases, Deaf women have been expected to use male interpreters for consultations on personal medical problems.

■ Action for change

- Provide Deaf awareness training for staff at all levels and include Deaf and partially Deaf people in staff training.
- Ensure that adequately qualified interpreters are available; that they adhere to the accepted CACDP code of conduct; and that they meet the specific requirements of the individual Deaf person.
- Make commonly used health promotion information (e.g. ante-natal information, available on signed video).
- Consider how community mental health services for Deaf people could be resourced.
- Investigate how professional training structures can be amended to enable more Deaf people to train in clinical settings.

DEAF PEOPLE FROM BLACK AND MINORITY ETHNIC COMMUNITIES

The gaps in service provision for Deaf people from Black and minority ethnic communities are even greater. Services provided by hearing impairment teams can fail to take account of different cultural needs, which can lead to the wrong type of support being offered.

■ Action for change

- Invite a group of Black Deaf people to recommend ways in which services can be made more responsive to the needs of Deaf people from Black and minority ethnic communities.
- Provide all written information in a variety of community languages.

DEAF PEOPLE WITH LEARNING DIFFICULTIES

Deaf people with learning difficulties want more direct consultation. They believe that their different needs have been ignored and they want more choices and opportunities. It is often wrongly assumed that because they are Deaf and have learning difficulties they cannot understand or make decisions that affect their day-to-day lives. Or it may be assumed that they do not need equipment, such as a minicom, which other Deaf people would receive.

Information is often presented in a way which is difficult to understand. Deaf people with learning difficulties sometimes do not want to ask for help in case this is mistaken for helplessness and them not being able to manage. Service agencies need to work with the Deaf community to explore ways of empowering Deaf people with learning difficulties.

■ Action for change

- Ensure that information is available to Deaf people with learning difficulties in pictorial form.
- Invite a group of Deaf people with learning difficulties to come together to give their views on the services they use and/or need.
- Consider how the use of relay interpreters can help Deaf people with learning difficulties participate in meetings more easily.

INVOLVING DEAF AND PARTIALLY DEAF PEOPLE

For services to improve and for improvements to be sustained, Deaf and partially Deaf people need to be fully involved in planning, implementing and evaluating those services. Consulting and involving users are not difficult in themselves, but do demand time, resources and commitment. Members of the Deaf community can be involved at several different levels:

- through individual feedback from services, assessments and outreach work;
- from public meetings or, even better, from focus groups or quality circles brought together to review services and to work on improving them in partnership with service purchasers and providers;
- by encouraging user-led organisations to bid for contracts to provide services such as interpreting or advocacy.

Deaf and partially Deaf people need to be involved in broader, cross-impairment consultation mechanisms where they can share in policy and decision making. They must also have the opportunity to become more closely involved in specific services, for instance in drawing up service specifications and setting quality standards. Some users may need access to training in order to develop the skills and confidence required to make the most of such opportunities.

Conclusion

This briefing can provide only a snapshot of some of the issues which currently affect Deaf and partially Deaf people's experience of community care. However, issues change, and health and social service agencies need to adopt ways of involving users which give them ongoing feedback on how to improve practice. Health services, in particular, must take a more active role in consulting with the Deaf community and working in partnership. Investing in user involvement can reap multiple benefits by improving services for Deaf and partially Deaf users, increasing motivation and job satisfaction for professionals and making more cost-effective use of scarce resources.

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References

1. RNID, March 1993.
2. Panel of Four. *Communication is your responsibility: The report of the Commission of Enquiry into Human Aids to Communication.* London: Panel of Four, 1992.

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This Briefing is also available on tape and in Braille on request.

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