Deaf people's participation in local services

A project by the British Deaf Association, working with Deaf people who use British Sign Language (BSL), found that the Deaf Community can help ensure the involvement of Deaf people in local services but that a number of measures are necessary to ensure their participation is effective. The project found:

- The presence of Deaf staff in agencies increased Deaf users' confidence in services but Deaf staff sometimes experienced conflicting priorities. The employment of a Deaf person as an independent 'honest broker' meant Deaf people felt that their culture was being fully acknowledged and also assisted agencies in highlighting difficulties in responding to Deaf people's needs.

- Voluntary organisations for Deaf people had more developed systems for participation than social services but Deaf representatives were not always clear what their role was; the presence of Deaf people at decision-making meetings did not guarantee their participation without specific action being taken to ensure this.

- The needs of doubly disadvantaged Deaf people (including Deaf people with disabilities and Deaf people from ethnic minority groups) were unlikely to be represented unless specific action was taken to enable their involvement.

- The researchers conclude that the Deaf Community offers service purchasers and providers a firm foundation from which to begin building involvement and participation but:

  - the communication demands are different from those of hearing people;
  - lack of accessible information seriously inhibits Deaf people's ability to participate effectively;
  - poor levels of investment into Deaf Clubs diminishes their potential contribution;
  - training in skill-building, assertiveness and confidence raising is essential if Deaf people are to participate effectively;
  - social services staff also need training about the Deaf Community, its culture and about British Sign Language and must be prepared to adapt their procedures accordingly.

At the time the project started in Autumn 1992 little was recorded on how Deaf people were involved in the social services they received. Most involvement was ad hoc and only became public if a crisis occurred. As consultation, involvement and participation moved up the agenda in social services the project produced the first record of a systematic attempt to involve Deaf people in a variety of settings.

Drawing on established networks the project employed a Deaf project worker who was bilingual in British Sign Language and English and was a member of the Deaf Community. He worked exclusively with the Deaf Community to try to develop systems which would be accountable and sustainable.

The services referred to in the project are specialist services provided by the voluntary and statutory agencies which were beginning to feel the impact of the community care changes. In the early days of the project the question of how the purchaser/provider split would affect Deaf services was unresolved. In these circumstances it was difficult for staff to be clear with Deaf service users about how procedures would evolve.

The importance of Deaf workers

The project found that Deaf people in all the partnerships praised the use of a Deaf person to work at the interface between services and service users. They felt it acknowledged and valued their culture and language and gave them much more confidence in the motives of the agencies.

> *"It supports the Deaf Community and will improve the community eventually."*
> A Deaf service user (translation from BSL)

The presence of Deaf staff in all of the agencies similarly gave out positive messages to deaf people and they felt those agencies were more approachable. However, the roles of Deaf staff were sometimes blurred if they were expected to represent service user views, although they could act as positive enablers of Deaf people if this was consistent with their post.

Establishing effective partnerships

Before the partners could be brought together a great deal of work had to be undertaken, firstly to negotiate agreed aims for the partnerships and secondly to prepare both sides so they could work effectively together. With hardly any of the written material available on social services and Community Care in a format accessible to Deaf people (such as BSL video versions) they were at a serious disadvantage in meetings. Deaf people whose first language is BSL found the information gap compounded if the meetings themselves were held in English, even when a Sign Language Interpreter was present. Most of the agencies had tried such meetings and both Deaf people and the agencies were not satisfied they offered real opportunities for consultation.

> *"Community care meetings are arranged at too short notice and not enough information is provided for Deaf people."*
> A Deaf service user

Deaf Clubs have rarely attracted outside attention. They are the major focus of Deaf-led activity concentrating primarily on social and sporting activity. The project found that lack of investment undermined the contribution Deaf people could make through Clubs. Relatively modest amounts of resources released to Deaf groups for developmental work could unlock reserves of talent. Without specific work within Deaf Clubs the basis for participation of Deaf people in external agencies is diminished.

In only one of the partnerships were black and ethnic minority Deaf people involved, and disabled Deaf people in one other. Even in the voluntary society with a high membership of Deaf people from ethnic minority groups, they were not visible on decision-making bodies. Addressing these gaps poses a major challenge for agencies, voluntary societies and the Deaf Community.

The agencies' approach

Social services departments approached by the project were very keen to be involved, but one department involved initially had to be excluded because frequent staff changes made it impossible to negotiate an agreed area of focus for the work. Those involved in the partnerships had backing from directorate level, with the project providing input on issues of Deaf awareness to two senior management teams. It was important that both Deaf people and agency staff had both explicit agreements on what they were trying to achieve and time to explore each other's expectations.

Staff involved in the face-to-face meetings with

Deaf service users had to be willing to share power and to make changes as a result of the comments from Deaf people. It was impossible for Deaf people in any of the settings described to make any changes without the agreement of staff involved. In the long term if Deaf people do not see any difference in the services they receive they will undoubtedly withdraw from involvement. Purchasers, in particular, have a unique opportunity to involve Deaf people in deciding when services are provided and how.

Agencies needed to be prepared for the time and the resources and energy required to make participation a reality. It is the agency's responsibility to support their potential partners to arrive at a point where they are informed, confident and clear about their involvement. The project found most of the agencies could not do this without outside assistance. Even in the voluntary sector agencies where strenuous efforts had been made to involve Deaf people an independent worker was able to identify barriers more successfully. It was particularly important that users in a closed setting, such as a Psychiatric Unit, or vulnerable groups such as Deaf people with learning difficulties had access to people independent of their service providers. Only by building these links and trust did the Deaf people involved feel free to make their views known and have their rights protected.

Although the culture of voluntary organisations may feel more user-friendly to Deaf people (especially when they employ Deaf staff), this does not mean that the barriers against involving Deaf people have been dismantled. Even where there was a longer track record of user participation the numbers of Deaf people volunteering to become involved was small. Very few black and ethnic minority Deaf people were involved. One of the voluntary agencies had set up groups for Asian women and men and it was from these sources that the only Deaf Asian users were recruited to the project. This suggests that unless specific measures such as this are employed little will happen.

Deaf people were not always clear of their role and responsibilities as representatives. One Deaf member of a voluntary society committee asked "Why am I here?". Action has to be taken to ensure Deaf representatives can function: this includes plain English summaries of minutes, briefings in BSL, chairs of meetings skilled in conducting such meetings, availability of interpreters and a system for communicating information to and from the wider Deaf membership.

Training

A major training programme with Deaf people was introduced using Deaf contributors. It aimed to fill some of the information gaps, to start Deaf people thinking about representation and to build skills they felt they required to feel competent to work in the partnerships.

Whilst the numbers involved in training were not large, Deaf people were very enthusiastic about learning new things. They particularly valued the assertiveness training and the opportunity to understand, often for the first time, social services jargon. Deaf people were concerned about the low numbers participating and about how they could work democratically within their community.

Staff and committee members involved in meeting users also needed information about Deaf people. Although many of the staff involved in the project were specialists in various aspects of community care planning, they were included in the training to help them see the world through Deaf people's eyes.

Conclusions

- Building effective partnerships to enable Deaf service users to participate in services is far from easy. Service purchasers and providers need to view it as a long term process and to develop a strategy with Deaf people.

- No single method or approach will reach all sections of the Deaf Community. A variety of approaches should be tried, including outreach, developmental funding, workshops, role plays and trust building exercises in addition to more traditional meetings.

- Deaf people prefer a Deaf person as a link to purchasers and providers. They also prefer face-to-face meetings in BSL.

- Significant investment in training is required for both Deaf people and their agency partners. Some agencies may need to look outside for the necessary expertise.

About the study

A Deaf development worker explored the barriers to effective involvement of Deaf service users and promoted partnerships between local Deaf service users and those providing services in five locations in the Midlands. Two social services departments, two local voluntary societies for Deaf people and a regional Psychiatric Unit were recruited to the project.

Further information

Copies of the full report, Visible Voices, on the work of the project and a diagrammatic representation of the Findings are available from:

British Deaf Association, 38 Victoria Place, Carlisle, Cumbria CA1 1HU. Tel: 01228 48844 (Voice & Minicom) 01228 41420 (Fax).

Related *Findings*

The following *Findings* look at related issues:

45   Development and training for self-organised groups of disabled people (Jan 94)
49   Disabled people and community care planning (Apr 94)
50   User empowerment and the reform of community care (May 94)
60   Self help groups and professionals (Nov 94)

The following *Summaries* are also relevant:

3   Developing user- and carer-centred community care (Mar 95)
4   Increasing user control in social services (May 95)
5   The development of self help activities (Aug 95)

For further information on these and other Findings contact Sally Corrie on 01904 654328 (direct line/answerphone for publications queries only).