

# Living Options Partnership Practice Briefing

QBBA (Kin)

## Improving services for blind and partially sighted people

### Introduction

There are approximately 1,000,000 blind or partially sighted people in the UK, 90 per cent of whom are over 60 and only a quarter of whom are registered.<sup>1</sup> Despite these significant numbers, blind and partially sighted people typically seem to receive very low levels of service and report experiences of services which are either inadequate or non-existent or simply inappropriate. The low priority given to services for blind and partially sighted people appears to be reflected in poor staffing levels in specialist social work teams for this group.

This documents builds on work carried out by a group of blind and partially sighted people who were invited to identify the issues which they considered to be most important in shaping their experiences of community care. It highlights gaps in services and offers some practical suggestions for making services more responsive to the needs of people with visual impairments. It is aimed at purchasers and providers (both managers and practitioners) in health and social services. For practical reasons, it focuses primarily on health and social services; these, however, are not the only, nor indeed the most important, concerns of blind and partially sighted people. Employment,

education, transport and housing also have profound implications for quality of life. Some of the issues raised are specific to people with visual impairments, others have implications for service provision to all disabled people.

### INFORMATION

Blind and partially sighted people continue to be denied access to services because information is not readily available in formats that they can use. Sometimes, even a simple measure such as changing a print cartridge or upgrading a printer can have dramatic effects on the accessibility of the information to a partially sighted person.

### ■ Action for change

- Provide all basic information about services in large print (minimum 14 point), in Braille, on tape and in pictures. Keep it simple and free of jargon.
- Ensure that information in local community languages is also available in these formats.
- Use the local authority Register of Blind People, local user networks, older people's organisations, newsletters and mailing lists to target appropriate information on

services. Also target opticians and GPs – they are often the first point of contact when a person first becomes visually impaired.

- Consider ways of pooling resources to establish fast and efficient transcription services (e.g. in partnership with neighbouring areas or using joint finance).
- Help user-led organisations bid for contracts to provide transcription services.

## ASSESSMENT

Many blind and partially sighted people feel that there is a profound lack of understanding about their needs. They find it difficult to ask for services because they have received inadequate support in the past and they do not want to undergo a potentially intrusive assessment with little likely benefit. Even when their needs have been identified, blind and partially sighted people often feel that needs are not met because they are not considered serious or life-threatening when compared with the needs of other groups. The criteria for entitlement to services (and assessment) are not made clear, and many blind and partially sighted people do not understand how a needs-led assessment should work. Finally, many blind and partially sighted people are discouraged by long waiting lists, means assessment and charges for services.

## ■ Action for change

- Involve blind and partially sighted people in training for care managers.
- Provide information in appropriate formats about how needs-led assessment should work.
- Carry out joint assessments between social services, health, housing and education departments when appropriate.
- Encourage self-assessment – blind and partially sighted people are in the best position to judge their own needs.
- Ensure that independent advocacy and interpreters such as deaf/blind communicators are available at times of assessment, review and whenever required.
- Encourage care managers to share ideas on holistic approaches to assessment and to develop resources on innovative ways of giving blind and partially sighted people control over the support services that they need.
- Ensure that blind and partially sighted people receive information about the outcome of their assessment in a suitable format as well as verbally.
- Record unmet need and feed this back into the planning process.

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## RESPONDING TO INDIVIDUAL NEED

Many blind and partially sighted people not only find it difficult to access services, but also find the services that they do use inflexible, disabling and delivered in a way which patronises or alienates them.

For instance, home care services are often only available to do shopping but not cleaning, ironing or to help with reading private letters – activities which may be much greater priorities for the individual concerned. Help with childcare responsibilities is also very difficult to obtain. It is often wrongly assumed that children can provide the support needed, for instance acting as readers, even though for some confidential issues this may be quite inappropriate. The majority of blind and partially sighted people are women, and yet their specific needs are rarely acknowledged. Lack of reliability in services can also be a problem. For example, users of a home care service may not be informed if the service cannot be provided on a given day. 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 blind and partially sighted people to identify and overcome the physical, 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, sexuality, age, religion or class.

### ■ Action for change

- Recognise that, since the needs of blind and partially sighted people vary widely and change with time, services should be tailored to meet individual need.
- Consult with local user-led organisations. Commission them to bring a group of people with visual impairments together to consider how existing services could be modified to meet a wider range of needs and what entirely new services might be required.
- Consider how the needs of blind and partially sighted women, especially those with childcare and other caring responsibilities can be better accommodated in planning services.
- Use and adapt the independent living model as a framework for needs-led service provision.
- Offer blind and partially sighted people delegated control over individual personal assistance budgets, access to independent living advisers or the opportunity to learn from existing personal assistance users.

## Independent living

Independent living is usually 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 blind and partially sighted people of all ages require to be independent:

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

- control by users over individual budgets.

Blind people who require help with reading correspondence, cleaning, shopping and mobility may value the flexibility offered by employing one or two workers to provide a range of support.

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 people with visual impairments.

## TRAINING

A key cause for concern is the apparent lack of training in equality issues for service personnel. This results in poor understanding of the needs of people with visual impairments and can lead to inappropriate attitudes and behaviour towards users. For instance, a blind person may be pushed into a waiting room from behind by a receptionist, instead of being led by the arm, or a doctor may fail to introduce all those who are present at a consultation.

## ■ Action for change

- Include structured disability equality training in targets for staff training at all levels (including senior managers).
- Use only experienced disabled trainers and include input from people with visual impairments.
- Avoid simulation exercises (e.g. smeared glasses, blindfolds) as they can give a distorted impression of the experience of living with a visual impairment.
- Introduce training for officers concerning the change in their professional role. Encourage them to value users as partners in planning, providing and evaluating services.

## HEALTH ISSUES

Blind and partially sighted people report both attitudinal problems from health service staff and lack of access to health services as major concerns. When other clinical issues are being investigated, blind people are often asked about their sight loss even if it is irrelevant to the situation in hand. Confidentiality can be ignored (e.g. personal details are discussed in front of other patients) and access to records is often denied. Medical assessments for insurance or benefits purposes are often made by doctors who do not know the person concerned and who are not sufficiently familiar with the needs of blind and partially sighted people.

It is especially important that access to good information on health and to regular check-ups is made as easy as possible since not being able to detect symptoms (e.g. blood in urine) can have potentially fatal consequences.

### ■ Action for change

- Commission a visually impaired user consultant to draw up a code of practice for staff dealing with blind and partially sighted people. The code could be developed and piloted in an eye-clinic before being disseminated more widely.
- Ensure that medical records can be transferred to accessible media if required, or that blind and partially sighted people can have records read to them. Make personal information such as appointment cards available in large print.

- Emphasise the importance of assessing individual need and listening to the patient in clinical training and make better use of specialist referrals.
- Ensure that signposting in hospitals and clinics is clear and well lit.
- Establish a patient/staff liaison group at the local hospital and ensure that people with visual impairments are represented.

## AIDS AND EQUIPMENT

Blind and partially sighted people report long delays in receiving vital pieces of equipment. Some essential equipment such as Braille writing-machines may be impossible to obtain at all. Endless bureaucratic procedures are often endured in order to obtain a simple piece of equipment such as a magnifying glass.

### ■ Action for change

- Invite a group of service users to work with managers on simplifying procedures for obtaining equipment.

## RECRUITING BLIND AND PARTIALLY SIGHTED STAFF

One way in which health and social services providers can increase the awareness and understanding of the needs of blind and partially sighted people among their staff is simply by recruiting more people with visual impairments. This applies as much to non-specialist as to specialist posts.

## ■ Action for change

- Advertise jobs through national and local disability organisations and make use of local radio and mailing lists.
- Ensure that job descriptions, person specifications and other details are available in a variety of formats.
- Ensure that up-to-date information on support available through the Department of Employment's local placement advice and counselling teams (PACTs) is obtained and used (e.g. computer equipment, reader services).

## TRANSPORT AND MOBILITY

It can be very difficult for blind and partially sighted people to find their way to public buildings such as hospitals, especially by public transport. This problem is magnified in rural areas. And yet, only 5 per cent of all people with visual impairments have received any form of mobility training.<sup>2</sup> One blind person reported spending seven years totally housebound because of lack of information. Where financial help with transport costs does exist, it is often difficult to access. In some areas, it is not possible to have a bus pass *and* use community transport services. Many people prefer to use minicabs for safety reasons.

## ■ Action for change

- Consider how mobility training can be made more widely available.
- Ask blind and partially sighted people how services could help them overcome transport barriers.
- Provide drivers/escorts with training in face-to-face work with blind and partially sighted people.
- Ensure that volunteer driver schemes are not the only option. Many people do not wish to rely on volunteers for essential activities.
- Ensure that bus passes, community transport and taxicards can all be used by the same person.

## PEOPLE WITH MULTIPLE IMPAIRMENTS

People who have multiple impairments often find that health and social services personnel focus on one impairment at the expense of another. Clinical needs are rarely assessed together, and this may lead to lack of co-ordination in the provision of services as well as frustration for the individual concerned. For instance, as many as a third of all people with learning difficulties also have a visual and/or a hearing impairment. However, they may not be tested for sight loss or offered the same opportunities to use guide dogs or white canes as other blind people. Facilities such as hospitals or day centres often do not take account of sight-related needs.



## ■ Action for change

- If possible, consider the clinical needs of the person as a whole. When several health professionals are involved, consider how one person can be given lead responsibility for a co-ordinated approach.
- Ensure that the focus of assessment and service provision is on meeting needs as a whole rather than on specific impairments.
- Ensure that people with multiple impairments have access to mobility and daily-living skills training.
- Check whether clients with learning difficulties have had sight tests and be prepared to challenge assumptions about what other services or equipment they might need to use.

## **BLIND AND PARTIALLY SIGHTED PEOPLE FROM BLACK AND MINORITY ETHNIC COMMUNITIES**

Blind and partially sighted people from black and minority ethnic communities find it especially difficult to access services which meet their needs. Not only are they less likely to receive information on existing services, but the services available often fail to take cultural differences into account. In a survey carried out by the Association of Blind Asians in 1993, nearly 60 per cent did not have any specialist equipment such as

reading or writing aids or specialist lighting, and only 23 per cent had access to a reader. Nearly 70 per cent had not received any training to help with day-to-day living.<sup>3</sup>

## ■ Action for change

- Promote the availability of services via existing networks and organisations of people with visual impairments from Black and minority ethnic communities (e.g. using cassette magazines).
- Ensure that information about who uses services is available through ethnic monitoring.
- Employ more staff from black and minority ethnic communities.
- Help visually impaired users from minority ethnic communities come together to support each other and to comment on services. Act on the feedback obtained.
- Consider funding a drop-in centre where users can go for mutual support and to access information, advocacy or interpretation services.

## **INVOLVING BLIND AND PARTIALLY SIGHTED USERS**

For services to improve and for improvements to be sustained, blind and partially sighted people need to be fully involved in planning, implementing and evaluating those services. Consulting and involving users are not difficult in themselves, but need time, resources and commitment. Practical details such as providing transport and accessible

information for meetings need to be efficiently managed.

Users 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 transcription, advocacy or mobility training.

Blind and partially sighted 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 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 blind and partially sighted 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. Investing in user involvement can reap multiple benefits by improving services for blind and partially sighted users, by increasing motivation and job satisfaction for professionals and by making more cost-effective use of scarce resources.

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## References

1. Bruce I, McKennell A, Walker E. *Blind and Partially Sighted Adults in Britain: The RNIB survey*. London: HMSO, 1991.
2. See 1.
3. Javed K. *Survey into the Needs of Visually Impaired Asians*. London: Association of Blind Asians, 1993.

g is also available on tape and in Braille on request.

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