THINK DUAL SENSORY

GOOD PRACTICE GUIDELINES FOR
OLDER PEOPLE WITH DUAL SENSORY LOSS

Also available in braille, cassette, and on computer disc

DEPARTMENT OF HEALTH

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THE DEAFBLIND PERSONS' CHARTER

- developed by Deafblind UK (formerly The National Deafblind League) and presented to 10 Downing Street during Deafblind Week, June 1995

* We, as deafblind people, are rightful members of the community. We deserve respect as individuals and the opportunity to participate fully in society.

* We, as deafblind people, have a wealth of skills and abilities. These should be recognised and our development encouraged, through education, training, employment and leisure.

* We, as deafblind people, may have special mobility and communication needs. These needs should be recognised and met.

* We, as deafblind people, are consumers of goods and users of public services. As such, we have a right to full information, access and choice.

* We, as deafblind people, can be isolated. Health and social service providers should be pro-active in identifying, assessing and meeting our needs.
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"I'm deafblind and so was my husband. I've not been out since he died 8 years ago. I hate being alone. I've learnt to close my mind so I don't have to think about it."

"I'm 81. I can't really see and now my ear drum's burst I can't hear very much. A social worker comes now and again and I have voluntary visitors from 3 different groups. One helps me get to church, another takes me out to play dominoes each week, and the third visits me here at home. I've no complaints, except I don't meet enough men."
1.1 Purpose of the document

1.1.1 This document sets out good practice guidelines for social and health care services in relation to older people for whom the normal ageing process is further complicated by a significant degree of dual sensory loss.

1.1.2 The information contained in the guidelines is up to date at the time of publication. Inevitably, given the increasing interest in the subject, some material will soon be replaced by other developments, and new information will become available. All this is to be welcomed. At the time of writing the document, it was impossible to forecast the impact of either direct payments or the Disability Discrimination Act 1995 on people with dual sensory loss. Those seeking information on these matters should consult the organisations listed in Appendix 3, under Resources and Contacts and refer to Department of Health guidance.

1.2 What do we mean by dual sensory loss?

1.2.1 Dual sensory loss is used in this document to refer to people whose combined sight and hearing losses cause difficulties with communication, access to information, and mobility. It may also be called deafblindness, and both terms are used throughout the text.

1.2.2 People who have dual sensory loss are among those who are most disabled by the norms of our society. We take it for granted that our eyes and ears will enable us to communicate, to observe the actions of others, and to form relationships and express our feelings with others.

1.2.3 Any degree of loss of sight or hearing can result in confusion, loneliness and isolation. Lack of information removes the ability to make informed decisions and also threatens independence. The loss of conventional methods of communication can have devastating social and emotional consequences. The loss of mobility can mean the loss of independence and daily living skills.

1.2.4 Deafblindness affects people in varying ways, and a fundamental understanding of the significant and unique effects of this disability is a necessary prerequisite to the planning and provision of services.

1.3 Who are older deafblind people?

1.3.1 There are enormous differences between individuals, including those who are or become affected by dual sensory loss. Deafblind people are as varied as those from any other group of citizens, and the nature, degree and onset of their deafblindness will vary also.
1.3.2 Five groups of older deafblind people can be distinguished, as a useful way of providing a wide framework in which to plan and deliver services, but all work should strive to acknowledge and be responsive to the uniqueness of each individual. The five groups are these:

* Those whose dual sensory loss has developed in old age. Most of the people meeting the broad definition of deafblindness used in this document fall within this group, and most of what follows is applicable to them.

* Older people who have adapted to blindness or partial sight during their life, and are now losing their hearing.

* Older deaf, deafened or hard of hearing people, whose usual means of communication is speech, and who are now losing their sight.

* Older deaf people whose usual means of communication is sign language or English signed systems, and who are now losing their sight.

* Older people who have had dual sensory loss throughout all or most of their life.

1.4 Background to the document

1.4.1 The document arises out of the work of a Department of Health Steering Group which consists of representatives from voluntary and statutory providers of health and social care services. The Steering Group was established in response to the concerns expressed by the Deafblind Services Liaison Group and Age Concern about the lack of good services for older deafblind people.

1.4.2 Earlier work had raised the needs of deafblind people of all ages. Two important publications were Breaking Through (Deafblind Services Liaison Group, 1988), which provided a framework for local authorities to consider the needs of deafblind people, and Signposts (SSI, 1989), which suggested recommendations for action by social services departments.

1.4.3 The Steering Group has gathered examples of good practice being planned and implemented, and it draws on these in compiling this document.

1.4.4 It has also benefitted greatly from the twelve-month consultation period on the guidelines in draft form. During this time, local authorities were invited to pilot one or more aspects of service provision touched on in the draft document. We were heartened by the enthusiasm and commitment of all who took part and who, through workshops, took advantage of the encouragement, support and advice of the SSI and other participating authorities. These guidelines highlight some of their work, both in the text and in Appendix 2.
We are grateful, also, for the helpful suggestions received from other agencies and individuals.

1.4.5 The work of the Group revealed a considerable gap between aims and achievements in relation to services for older deafblind people. The consultation period highlighted the progress that can be made when committed practitioners and managers pool their experience and expertise. The document poses some of the key questions that might usefully be explored by those working to improve the quality of life of deafblind people by increasing their independence and their ease of access to the many and varied aspects of daily life.

1.5 The philosophy behind services for deafblind people

1.5.1 The Group's work has been underpinned by its belief that deafblindness is a distinct and complex disability that arises out of the particular impact of serious loss of both sight and hearing. As a result, services for people with a single sensory disability cannot provide adequately for the needs of those with dual sensory loss, although adaptations to services for blind people and for deaf people can render each of those services more responsive to the needs arising out of deafblindness.

1.5.2 A second key feature is the important role of health agencies and personnel. The boundary between health and social care must be crossed if the correct services are to be provided to people with dual sensory loss. The pilot work undertaken by both local authorities and health authorities highlighted the importance of close co-ordination between the two. The draft guidelines were weaker on this aspect of service planning and delivery, and weaknesses remain in this final document also. Where possible, however, we have drawn attention to the progress being made. One key development is joint work for Community Care Plans: getting this approach right for people with dual sensory loss can be one useful step to getting it right for other people, too.

1.5.3 Another guiding principle for the work is that the individual community care approach creates an opportunity to get things right for people. The following well-known principles about 'Living Options in Practice' are commended to local authorities for their work with deafblind people:

CHOICE about where to live and how to maintain independence, without over-protection or the risk of unnecessary hazards, including help in learning how to make choices.

CONSULTATION with people with disabilities, and their carers and families, on services as they are being planned.
INFORMATION that is clearly presented and readily available to all users, including those with severe disabilities.

PARTICIPATION in the life of local and national communities, in respect of both responsibilities and benefits.

RECOGNITION that long-term disability is not synonymous with illness, and that the medical model of care is inappropriate in the majority of cases.

AUTONOMY, meaning a person's freedom to make decisions about the way of life that is best suited to their individual circumstances.

These principles are similar to the NHS 'Maxwell Six' values: Equity, Efficiency, Responsiveness, Effectiveness, Appropriateness and Accessibility.
"When I go shopping I could do with a guide to bring the scene to life, so to speak, tell me the prices and the new offers. On one trip I did have such help and it made all the difference and I enjoyed it."

"I'm 80 now. I was registered deafblind when I was 72. But I was able to lipread, then I could read notes, then finally as my sight deteriorated I used the capital letter communication method on the palm of my hand. All this was successful."
2.1 Acknowledging the need

2.1.1 The Deafblind Services Liaison Group (DBSLG) estimates that, using a reasonably broad definition, for every 100,000 of the population in Britain there may be at least 40 people with dual sensory disabilities. This represents a wide spectrum of dual sensory loss, ranging from the relatively few who have total loss of sight and hearing to the many who have varying degrees of combined sight and hearing loss. Older people are more likely than others to develop both hearing and vision problems. Local authorities can assume that half of the over 75s in their area who have a visual disability will also be hard of hearing. They can also assume that the number of people in their area with visual disability will probably be about four times higher than the number on their register. (RNIB Needs Survey, 1991)

2.1.2 The problems created by dual sensory loss can lead to people becoming increasingly withdrawn, depressed and isolated. Yet, with the right help, deafblind people can live fulfilling lives both at home and in their community.

2.1.3 An important first step in developing services for deafblind people is to acknowledge that dual sensory loss affects a large number of people, especially older people, and that practical services can make an enormous difference to the quality of their life. The common perception that sensory loss in older people is a natural and inevitable part of ageing should be resisted, and the possibilities of overcoming or reducing its disabling effects should be emphasised. Some reports analysing these issues are listed at Appendix 3.

2.2 Raising awareness

2.2.1 The impetus for getting started may come from just one person, or from a variety of local and national sources. There is no right way to begin, and much will depend on whether you are starting from scratch or building on past work. Whatever the circumstances, an initial task will be to extend the awareness of dual sensory loss, and of the need for action, as widely as possible. This will have two advantages. First, it offers the possibility of harnessing everyone with an interest or expertise in the problems facing deafblind people. Second, the earlier that people are involved in discussing problems and possible solutions, the greater their likely ownership of ideas arising for action.

* The involvement of elected members, and non-executive members of health authorities, will help focus attention on the corporate responsibilities towards deafblind people as well as the duties and powers of individual departments and agencies.
* The early involvement of *local authority staff and health professionals* at all levels will help increase knowledge of each agency's skills and duties, and enhance the prospects of good working relationships and high levels of cross referral. Dual sensory loss needs to be recognised in health authority purchasing plans, and included in their corporate contract with regional offices.

* The *independent sector* providers - of residential homes, nursing homes and domiciliary services - will bring issues and concerns from their particular work with older people.

* *Voluntary organisations* will have much to contribute from their work with or on behalf of older people, with people with separate and dual sensory loss, and with members of ethnic minority communities who may have particular problems in gaining access to relevant services.

* *Deafblind people*, their families and carers, and friends, neighbours and other interested members of the public will provide essential and unique insights into current problems and preferred solutions.

2.2.2 Awareness raising at this early stage might include distributing leaflets and organising short workshops and meetings at different times of the day. The purpose of these would be to alert people to the likely scale of the problem, to demonstrate a positive wish to improve the quality of life of deafblind people, and to invite goodwill and co-operation between providers, voluntary organisations and current and future service users.

2.3 Deciding to respond

2.3.1 The response needed to improve services to deafblind people will depend largely on the extent and nature of what is provided already. Some local authorities may have no services; others will be forging ahead with imaginative schemes. The common features of a successful response cannot be overemphasised. They will include the recognition of deafblindness as a separate and unique disability, and the ability to identify the specific ways in which services are provided.

**Examples**

* In Sunderland, where a Sensory Disability Team has existed for some time, a Deafblind Forum was established in 1989, following the publication of *Breaking Through* (*DBSLG, 1988*). This led to research which identified 300 deafblind people, and the development of a deafblind register. In 1991, the recommendation of additional staff to the Sensory Disability Team led to the restructuring of the Team and the creation of the post of Officer for Deafblind People.
* In Wigan, the Sensory Disability Team took on the management and delivery of services to deafblind people some seven years ago. The Team has four specialist workers - two leading on visual disability and two on hearing disability - and two rehabilitation officers, one for hearing disability and the other for visual disability. Although each member of the team leans towards one or other sensory loss, there is full deafblind awareness and roles are largely interchangeable.

2.3.2 The key message is that some system is needed so that an outcome can be achieved, but it does not necessarily require a specialist dual sensory loss worker.

2.4 Identifying and locating users

2.4.1 It is essential to have as clear a picture as possible of the location and number of older deafblind people in the area. Whilst the collection, collation and analysis of data might appear a daunting task, there is a growing bank of guidelines and good practice, beginning with the Good Sense Guide (SSI, 1991), about useful methods of finding and categorising this information.

EXAMPLES
* In Leicester, a project worker for deafblind services, advised by a multi-agency planning and support group, was employed by the Leicestershire Society for the Blind to identify deafblind people in the county, collect information about the characteristics and needs of a representative sample of deafblind people and their carers, and make recommendations for the provision of services. After three years 1,462 deafblind people had been identified.

* In Sunderland, a core group working party on deafblindness employed a worker to identify deafblind people living in the authority. After six months 150 people had been identified as deafblind, with a further 150 waiting to be assessed.

2.4.2Whilst these and other areas have varied in the detail of this preliminary identification work, some common helpful pointers for practice have emerged:

* Agree a working definition of deafblind. Many areas have adopted the one used at the start of these guidelines.

* Initial contact with agency directors or chief officers can help pave the way for a positive response from staff at other levels.
* Be prepared to spend time meeting individuals and groups of workers, and doing follow-up letters and phone calls. The extra contact will be helpful, not just in ensuring staff refer potential deafblind people to you, but also in providing a wider awareness of the needs arising from dual sensory loss. Offer personal input ('free training') after initial contact.

* Make it easy for people to respond quickly to requests for referrals. The form used in Sunderland asked for only a few basic details - name, address, date of birth, whether the person lived alone, and whether they had other disabilities.

* Use publicity material as you trawl for information. The Leicester project produced a fact sheet about deafblindness, a guidance leaflet about their project, and two posters to inform the public and encourage people to refer themselves and others. One poster was in English and the other in four Asian languages.

* Contact as many people as possible within both the local and health authority. Include SSD staff in offices, day centres and residential establishments; staff in the home help section, housing offices, and advice centres; and those in other services such as leisure and recreation. Take advice from health colleagues about the best way of making contact with staff at all levels and in all settings. An approach to them from a health-based person, or a joint approach, is more likely to succeed than an approach from social services alone.

* Make contact with a wide variety of other sources outside the local authority, and reach out beyond professional workers. Besides the health authority mentioned above, include the employment and education service; voluntary organisations for deaf people, blind people and other user groups, including those serving ethnic minority communities; volunteer bureaux; local papers and TV and radio stations; and stalls in shopping and other public centres, to reach people who have deafblind friends and neighbours living in isolation.

* Information may be gained from cross referencing the Blind and Partially Sighted Registers, and the Deaf and Hard of Hearing Registers, although they are known to cover only some of those eligible and so must be used with caution.

* Be willing to include rather than exclude. Some people who fit within your definition may not require much, if anything, from a service for deafblind people, but it is better to include them at the start and allow them to judge that for themselves rather than preclude them from
the outset because the figures grow beyond initial expectations.

2.5 Auditing current services

2.5.1 Another preliminary task will be to take stock of the services that are already provided for people with either hearing or visual loss, or both. It will be useful to compile a snapshot view of what is available from different local agencies, and who gets access to these services. A brief standard questionnaire is likely to provoke a speedy response that offers information in a manageable form.

2.5.2 Include services provided by the SSD and other local authority departments, health services, other sensory services, services for the elderly in various types of accommodation, and both voluntary and private sector organisations.

2.5.3 This overview will provide a useful basis for your discussions about how existing services might be developed and new ones put into place. It will also be another mechanism for raising awareness of the need for specific services for deafblind people.

2.6 Consulting users and their carers and families

2.6.1 Consultation with deafblind people and their carers and families also needs to be part of the early thinking and planning stage. It will give service planners direct insights into the aspirations of deafblind people, as well as the difficulties that reduce their contact with people, limit their access to information, and restrict their independent movement from place to place.

2.6.2 Contact with carers and relatives might enable you to communicate more easily with the deafblind people you meet, and will offer the chance to understand the particular needs of those who care for and about them.

2.6.3 There are various ways of consulting at this early stage, including personal meetings, the collection of user profiles, and user involvement in planning meetings. All these forms of consultation will require attention to communication support if they are to be used to best advantage. (See Chapter 3 for further discussion.)
KEY QUESTIONS

1. How do you ensure that deafblindness is recognised as a separate and unique disability?

2. In what ways do you seek to identify local deafblind people? How many are there in your area?

3. Who is responsible for the overall delivery of services to older deafblind people in your area? Who is responsible in the health authority? How are the responsibilities defined? How do they link with the duties of others in each authority?

4. What services are provided locally and regionally for deafblind people by other statutory agencies, voluntary organisations, and other groups and individuals?

5. How might you enable other agencies in your area to be aware of, and responsive to, dual sensory loss - in order to help identify the potential need for services?

6. Might more ethnic minority people with dual sensory loss use your day care and other services if activities and refreshments were more sensitive to their culture?
"It's the little things that I fancy, like knowing how to use the microwave, and how to tell when someone's at the door."

"It would be wonderful if there was an understanding and patient Guide-Help on a regular basis, or available on request, willing to help in all sorts of ways, maybe type out some letters I dictate, or take me for a walk such as on the beach or promenade now I can no longer go alone. That reminds me of the sound of the sea rushing in over the shingle, wonderful music."
3 SETTING UP NEW SERVICES

3.1 Introduction

3.1.1 Ideally, the thinking and planning about service development for older deafblind people will have provided a wealth of information: about how many potential users live in the area, and where and in what circumstances; about any local services already in place; and about the direct views of deafblind people and their carers. With this information, you will be well equipped for the next stage of the work: the development of co-ordinated services that cater specifically for the separate disability of deafblindness.

3.1.2 But life is not always ideal – you may not have much information before you begin to develop services. Collecting and updating data will be an ongoing process, as will the raising of awareness of as wide an audience as possible.

3.2 Devising a strategy for implementation

3.2.1 Moving things forward should be one person's responsibility. Whether you are starting from scratch or building on existing services, a designated senior officer within the local authority will provide a named contact for users and professionals, and will help stimulate and co-ordinate a rolling programme of work.

EXAMPLE

* In Bradford, a specialist social work post for deafblind people was created in 1992. The various tasks included defining deafblind people and identifying their numbers and needs, devising sets of service principles, undertaking assessment and care management duties, making links with other organisations, costing the resource implications of the needs identified, and negotiating for resources. Action has been taken on a number of fronts. A report to the Joint Planning Group was followed by consultation meetings with deafblind people and their carers, and a separate section in the council's 1994/95 Community Care Plan identified objectives and budgets for information, equipment and practical help. A Support Consultation Group - mainly for carers - was established in February 1995, to identify gaps in provision, and agreement was secured for a three-year development post, funded by Joint Finance.

3.2.2 The establishment of guiding principles at this stage will influence the quality and direction of future work.

* A commitment to tailoring your general service principles to the
specific needs of deafblind people will help ensure that meeting their needs remains the focus of work undertaken.

* So will a commitment from the start to finding effective ways of involving users in the planning, delivery and evaluation of services.

* An explicit acknowledgment that your growing knowledge will continue to be an underestimate of actual need will keep you alert to exploring new ways of making contact with potential users. Workers with older people often fail to recognise sensory needs. Mental illness or learning disabilities may mask the existence of deafblindness, or those who are deafblind may be wrongly diagnosed as having other difficulties instead. Members of community ethnic groups, and people living in residential accommodation, will need special attention as their needs are often overlooked by service planners and providers.

* Users, and staff, will be well served by your insistence on high standards, and the development of systems and services that draw on both good practice elsewhere and the principles outlined in documents such as the [Citizen's Charter](#), the [Citizen's Charter and People with Disabilities](#), and the [Informability Guide](#), produced by the Central Office of Information (1996).

3.2.3 The requirement of the Community Care Act to plan services for people with sensory disabilities provides a good opportunity to highlight the need for separate recognition of both sensory and dual sensory disability, to raise awareness of deafblindness, and to make public your commitment to provide specific services. Your Community Care Plan can also be a useful way of recording your achievements, and alerting people to any obstacles that might have limited your progress.

**EXAMPLE**

* Rotherham's Community Care Plan has a separate section on sensory disability. In addition, it distinguishes deafblindness from both visual and hearing disability. It lists, and comments on, the previous year's plans for developing Guide-Helps and carer support services. It promises three strands of joint action: on supported housing, day and respite services, and staff training.

3.2.4 Budgets need to be secured and ring fenced, and planned for flexible use. While it will be important for designated or specialist workers to be prepared to make the case for providing an expensive, specialist service to a small minority of elderly people, it is also true that large numbers of older people will benefit from staff awareness and other relatively inexpensive changes to services.
3.3 Assessment and care management

3.3.1 Attention will be needed to ensure that the assessment process clarifies the needs of deafblind people, and that any subsequent care management is organised, monitored and reviewed thoroughly.

3.3.2 Once a referral is received, the deafblind person and the person who referred them should be told what will happen next. There is often a long time lapse between referral and assessment. Good practice would suggest the setting of maximum waiting periods.

3.3.3 The assessor will need to establish the deafblind person's preferred mode of communication. Communication may be via a person (such as a carer, relative, friend, interpreter or advocate), or a method (such as large print, braille or the Deafblind Manual). Taking care to clarify this and incorporating the view of the deafblind person herself, will bring several benefits. It will avoid workers and others acting on wrong assumptions. It will signal a wish to establish a relationship with the user. It will enhance the status of both the user and her preferred communication method.

3.3.4 The assessment process should allow for the extra time needed to assess deafblind people properly. Some practitioners find that the initial assessment will usually take up to three hours, and is best conducted as two or more separate home visits. Users will generally feel safer if a known and trusted person is with them, and they should be encouraged to suggest an appointment time that makes this possible.

3.3.5 The purpose of assessment is to get as full a picture as possible of the person's needs. This will include looking at:

1. the degree of hearing and sight loss,
2. other health conditions,
3. communication needs - both expressive and receptive,
4. mobility and independence skills,
5. the potential for learning new skills and the appropriate time to introduce them,
6. support in the home,
7. equipment and adaptation requirements,
8. social work support,
9. welfare benefits and other finances, and
10. emotional and spiritual needs.

Carers' needs should be separately assessed from those of the deafblind person.

3.3.6 Everyone will need to be clear about who holds responsibility for developing, monitoring and reviewing individual plans.
3.3.7 Like the assessment, the care plan should be the product of work done in partnership by users and workers. Plans should be recorded in formats that enable users to keep their own copy, to mull over in the privacy of their home or with friends. Reviews need to be held regularly and, if they reveal changed circumstances, the care package should be adjusted as necessary.

3.4 Services and solutions

The following matters will need particular attention:

3.4.1 PUBLIC INFORMATION: This includes both general information - about services and events for all local citizens - and specific information - about services available to deafblind people. Full and accurate information is needed about how public services are run, what they cost, how well they perform, and who is in charge. As no one medium will reach all users, a range of styles and formats should be used.

3.4.2 COMMUNICATION: Understanding, and being able to bridge, the communication difficulties of deafblind people is a key factor in the provision of services. Since people become deafblind at different ages, and have many different degrees of visual and hearing loss, communication needs also vary greatly and are often very individual.

3.4.3 Deafblind people might already use or want to learn from among a wide range of communication methods. The document Making Contact (Sense, 1996) gives clear guidance about ways of consulting and communicating with deafblind people. Also relevant are the needs for interpreting languages other than English, and for considering environmental equipment such as fan operating and flashing light doorbells, and adapted phones, radios and TVS.

3.4.4 MOBILITY: People need to have confidence in moving safely around their rooms, garden and immediate neighbourhood of their own home or residential home. This may be with or without a recognised mobility aid, such as a white cane, red and white cane, or guide dog. The cost and lack of transport will be added obstacles for many people.

3.4.5 STIMULATION/RELIEF FROM ISOLATION: Help will often be needed to avoid deafblind people becoming, or continuing to be, starved of knowledge about daily events in the world around them, or of having too little contact with a range of other people.

3.4.6 SOCIAL WORK/COUNSELLING: For those who have become deafblind later in life, help may be needed to adjust to the distress of sight and hearing loss. Help may also be needed to overcome the fear and embarrassment of having to rely increasingly on other people's eyes and ears, or to overcome the
cultural difficulties in using touch for communication. These changes can have profound emotional and practical consequences for a person of advanced years, compounded by the other more general demands and anxieties of growing old. These may well need to be considered at length, and resolved or accommodated, by deafblind people and those close to them.

3.4.7 The rest of this chapter looks at the range of possible solutions to these specific needs of deafblind people and their carers and families.

SPECIALIST ASSESSMENT

3.4.8 High priority should be attached to having assessments conducted by workers who have validity in or with the agency, as well as having the necessary specialist skills. The benefit of specialist assessment is that it brings awareness of special deafblind needs. Non-specialist assessors may put problems down to age or vulnerability, not deafblindness itself, and so assess people under a general head such as 'elderly at risk'. What may be missed also is the opportunity to help people make best use of their residual hearing or vision, by learning about possible new ways of communicating. It is important, however, to guard against having only specialists, for skills also need to be developed throughout the team or service.

3.4.9 There are three options for developing specialist assessment:

1 **EMPLOY YOUR OWN** In some local authorities this work is included as a task of the specialist deafblind worker.

2 **GROW YOUR OWN** In other places the work has been taken on by staff who have acquired specialist skills in dual sensory loss, in addition to their existing skills in either sight or hearing loss.

3 **USE OUTSIDE SPECIALISTS** Several authorities have contracted the services of organisations who work with deafblind people, notably Sense, Deafblind UK, RNIB, and RNID.

COMMUNICATOR-GUIDE OR GUIDE-HELP SCHEMES

(These terms are used interchangeably in this document.)

3.4.10 The task of a Communicator-Guide is to enable a deafblind person to enjoy greater independence and a better quality of life. They have been described as "the telephone, the taxi, the television and the travel agent" for the deafblind person in their interaction with the world around them. The precise range of activities will vary according to the user's individual preferences and the details of the scheme in operation. Typically, they include visiting at home, to help with letters, phone calls, bills and phone calls, and escorting the user outside their home, to help with shopping, recreational and other activities. The Guide-Help's aim is to relay what is
seen and heard, to enable the user to make best use of what sight and hearing they may have, and to act as a companion. They have an important role to play in reducing the stress and increasing the confidence of deafblind people.

3.4.11 Whilst provision so far is limited to only a handful of local authorities, there are several well-established schemes in operation. There is also a vigorous debate about some aspects of the service: in particular, about the title, status and personal qualities of Guide-Helps, and about ways of providing and managing schemes. Some schemes are run by the local authority itself (as in Cambridgeshire), others may be contracted out (as in Wandsworth, where the RNID has the contract), and in others volunteers or home care assistants are the basis of the service, managed by either the SSD or a voluntary agency. Some authorities require Communicator-Guides to be trained to the CACDP minimum (see Touch and Go, 1994) and, if necessary, add other training in specific communication methods or cultural awareness.

3.4.12 These debates are likely to continue as schemes get implemented, reviewed and refined, and as user participation becomes a more regular feature of service provision. Local authorities are urged to enter this debate.

3.4.13 Free advice, about the different ways forward and the essential elements of Guide-Help schemes, is available from Sense (to authorities in the South of England), and from the RNIB (to authorities in the North), through a project supported by the Department of Health to increase the provision of these schemes. Free advice is available also from Deafblind UK, as part of its core work. Local authorities starting from scratch, with the numbers and needs of deafblind people unknown, might want to consider contracting in help from these and other specialist organisations. Sometimes funding of the provision of a Guide-Help can be made as part of a deafblind person's community care package.

EXAMPLES

* Norfolk SSD employs 16 part-time Guide-Helps who provide a service of, usually, two hours per week to 70 deafblind people. This covers half of the 142 deafblind users identified in the county. Help can be provided to those in residential care if isolation is a problem. The Guide-Helps are paid at grade 5 of the casual manual worker scale, but with enhanced travel expenses. They receive individual support from the specialist co-ordinator for deafblind services, have four development days each year, and must attend the fortnightly club for deafblind users. The service provides 1,000 hours per month at a total annual cost of £85,000. The SSD look to recruit people who are reliable and empathetic, usually through their previous experience with deafblindness. The main tasks are described as "shopping, socialising, doctors' visits, and organising the week ahead".
Wigan SSD employs 14 of its home care assistants as Guide-Helps. They have been identified as suitably experienced and have followed a three-day training course developed for them. The scheme has been running for two years. Users are consulted about who will be their Guide-Help. Providing a service in this way enables the Department to offer a range of skills by people who are already in touch with a wide group of social and health workers and are well placed to extend awareness of the needs of deafblind people. The disadvantages are that home care assistants are not allowed to transport users, and a charging policy applies to the home care service.

Wigan consists of small, fairly close-knit communities and in each of these social workers have good knowledge of the local agencies and schemes that can be harnessed for needs over and above the two hours that can be provided by Guide-Helps. For example, there are close links with religious groups, organisations for older people, and the Metro-tech government-funded scheme which is a twelve-month volunteering scheme for unemployed people, linked to the acquisition of NVQs.

* In Sunderland, Opportunities for Volunteers money (see Appendix 3) has been used to enable the local voluntary sector to work with the council in providing a Guide-Help scheme. The SSD screens all referrals and trains the selected volunteers; the voluntary agency takes responsibility for recruitment and regular supervision. The scheme reports that there have been few breakdowns between deafblind users and their volunteer Guide-Help, that it has been successful in helping people break out of their isolation, that demand is greater than supply, and that recruitment can be difficult and time consuming.

SPECIALIST EQUIPMENT

3.4.14 The equipment needs of deafblind people, and their difficulties in gaining access to them, highlight the crucial importance of 'thinking dual sensory'. Many pieces of equipment are geared towards the needs of people with only one sensory disability. For example, a deafblind person may find a clock useful if it has large numbers and tactile markings.

3.4.15 The cost of equipment is a source of frustration to many deafblind people in that equipment is advertised as available to help them, but at a price they can ill afford. Communication and alerting devices for people with dual sensory loss fall should count as aids to daily living that can be provided under the Chronically Sick and Disabled Act 1970 and the Disabled Persons (Services, Consultation and Representation) Act 1986. Authorities can help by supplying older deafblind people with a choice from among a wide range of aids such as fire alarms that flash, vibrate and ring loudly; doorbell and
phone alert systems; phones with amplifiers and induction loops; and phones that can be linked to braille and large character displays.

3.4.16 A separate ringfenced budget can be useful here - and for deafblind equipment, not just equipment adapted for visual or hearing disability - with equipment purchased when necessary from a national supplier and made available to users as a long-term loan. Bradford created a special budget of £5,000 for equipment last year.

3.4.17 Some authorities have set up Resource Centres where people with sensory disabilities can try out a range of aids. Other centres run rehabilitation and training courses where people can learn to use particular pieces of equipment. Both would be useful for deafblind people and their carers.

3.5 Support for carers and families

3.5.1 Good-quality services for the carers and families of older deafblind people should include information and advice about services, counselling and training, and respite care. Offering carers the opportunity for mutual support is also likely to be welcomed.

EXAMPLES

* In Bradford, a support group for Asian carers of deaf people has been organised.

* In Bristol, a deafblind social club meets every other month, on a voluntary basis. It is for deafblind people and their supporters or carers. Taxi and overhead costs are funded by the Bristol Royal Society for the Blind.

3.6 Consultation with users

3.6.1 Effective user participation in the planning and delivery of services will require the direct involvement of deafblind people in the development of both overall services and individual care plans. Carers and families, too, will have a wealth of knowledge and expertise that should be tapped as a resource for planning for services.

EXAMPLES

* Bradford has established a Support Consultation Group, mainly for carers, to help identify gaps in provision.

* North West Anglia Health Authority has developed a strategy for people with a physical and/or sensory disability. The process, called Healthy
Horizons, involves workshops for users - as well as for those who purchase and provide services - in which people identify what they value in current services and what their ideal services would look like. A final consensus conference leads to an action plan for refocusing services.

3.6.2 One important general principle is that consultation with users should be timed so that comments received stand a chance of influencing decisions. If not, consultation will be seen, rightly, as tokenistic. Other principles are about paying users for their travel, care and other costs; giving feedback after consultation; thanking people for their time and commitment; and explaining what ideas have been taken up and how.

3.6.3 In relation to consulting deafblind people, discussion will need to be in small groups, since each user present may well be using a different communication method. Clear rules will be needed about the conduct of meetings: about the need for introductions, about the availability of interpreters and mechanical aids to communication, about providing enough time for everyone to contribute at their ease, and for finishing in time for people to return home in the safety of daylight.

3.7 Implications for training

3.7.1 The success of the new services you are planning will depend, in large part, on people being well trained for the demands and expectations of the job they will be doing. First and foremost, they need to be sympathetic towards, and aware of, the effect of deafblindness on individual service users.

3.7.2 An appreciation of the time required to work with deafblind people, and the importance of doing things at a pace which enables them to act with confidence, are crucial messages to convey through training programmes.

3.7.3 Not all workers trained in the separate sensory specialisms will have had training in deafblindness; rehabilitation workers in visual disability, and social workers with deaf people, may need additional skills. Plans for training should also include all other relevant groups: elected members; head office and area managers in charge of field and residential staff and the allocation of resources; those who work with people with learning difficulties, given the particularly high incidence of sensory disability among this group of service user; and Guide-Helps, home care assistants, volunteers and others who visit deafblind users at home.

3.7.4 Reception and administrative workers are key personnel, too, since they are often the first and most regular contact persons in the department. In Sunderland, six of the twelve administrative staff in the SSD have had
training in proficiency in communicating with deafblind people, and some are now learning British Sign Language.

3.7.5 The training of all other staff groups should include some input on the needs of older people with dual sensory loss, in order to highlight the importance of being alert to users who might be finding it increasingly hard to see and hear well.

3.7.6 Specialist workers will need access to a wide range of training, to keep themselves up-to-date with developments in law and practice. They also need opportunities to meet a range of other staff, to guard against their becoming marginalised within the authority.

3.7.7 Deafblind users and their carers have an important contribution to make to staff and volunteer training, especially about awareness and practical skills. But they may well need some training for themselves, about, for instance, how best to pass on their knowledge and expertise.

3.8 Planning and securing resources

3.8.1 People with experience of introducing the sort of services described above point to the importance of adopting a strategic approach to the question of resources.

3.8.2 Managers will need to be effective in estimating the costs involved and the likely sources of funding, pressing the case with key providers and purchasers, and being prepared to advocate vigorously on behalf of a group of service users who have traditionally been few in number and low in profile.

3.8.3 These factors themselves form part of the case for resources being allocated to services for dual sensory loss. One of the advantages of specialist services is that they get to those people who have not been reached for reasons explored earlier: they may hide their disability through fear, or embarrassment, or wanting to remain 'safe' in their isolation; or their deafblindness may be masked by or mistaken for other conditions. Others who are deafblind get missed for other reasons, such as living in residential care or being from a minority ethnic group, neither sought out nor noticed by service planners and providers.
3 SETTING UP NEW SERVICES

KEY QUESTIONS

1. Do specialist workers provide specialist services to deafblind people in your area? Are specialists in one sensory loss required to learn about the other specialism?

2. How have you identified and provided for the particular needs of people from your local minority ethnic communities, when planning services?

3. How do the assessment processes identify the needs of older deafblind people? Is this work undertaken by workers with specific skills?

4. How do you identify and provide communication support for users during the assessment process?

5. How is assessment information shared with users and carers?

6. How do you consult with, and inform, deafblind users and their carers and families about service planning? What are the resource implications and the impact of user involvement? How could health and social services consult users together?

7. What support groups or structures have you established for users and carers, and for deafblind users and their carers?

8. How have you provided for the need for specialist equipment?
"They should make sure the deafblind manual is taught to people in local authorities and in the services it provides, its police, ambulance, the social services, in the hospitals, and any place that may be of help."

"It would be wonderful to sample all the types of equipment that are now available and which might make life less stressful and more fulfilling."
4 DEVELOPING EXISTING SENSORY SERVICES

4.1 Introduction

4.1.1 This chapter explores ways in which existing services for those with a single sensory loss can be used and developed to cater for the specific needs of those with dual sensory loss.

4.1.2 The questions to be posed relate to how general sensory services are managing to make specific provision for deafblind people. There are wide gaps in our knowledge of how this is being done, but we set out below some of the approaches that we have come across.

4.2 Making use of existing services

USING REGISTERS

4.2.1 Local authorities are obliged to keep Registers of Blind and Partially Sighted people, and Registers of those who are Deaf and Hard of Hearing. Where registers are kept up to date they are useful tools for identifying which older people come under both categories.

4.2.2 Planning for the relatively small group of deafblind people in an area can be made easier by the compilation of one single register for those with dual sensory loss.

USING FORM BD8

4.2.3 The BD8 form is completed by consultant ophthalmologists, to certify people as blind or partially sighted. In Sunderland, all BD8 form on older people received by the SSD are passed to the Team Leader of the Sensory Disability Team (SDT) and redirected to the older persons' team (for over 65s) for a holistic assessment within 28 days. The assessment is returned to the SDT Team Leader. The only exception is that BD8 form referring to deafness are routed direct to the rehabilitation worker with deafblind people. Assessments have sometimes highlighted the fact that hearing loss has not been indicated on the BD8, despite the user's significant hearing disability.

JOINT ASSESSMENTS

4.2.4 In Bradford, where assessments are the responsibility of the specialist deafblind worker, home visits are sometimes made jointly with a rehabilitation officer who can then offer advice and subsequent training in low vision aids and mobility.

4.2.5 In Wigan, where there is no deafblind specialist, joint visits are made, where necessary, from the Sensory Disability Team - by one of the social workers for the visually impaired and one for the hearing impaired.
REFERRAL SYSTEMS

4.2.6 Referral systems will work well if a wide variety of people know about them, know how to use them, and can see the benefits of using them. Wigan's referral system to the Sensory Disability Team involves hospitals, other health services, residential care homes and independent notification. The Team reports a high level of referral from social workers.

CHECKING WHAT WORKERS KNOW

4.2.7 In Leicester, the development work for deafblind people began with the project worker asking members of the Sensory Disability Team to say who they knew who could be described as deafblind. The same question could be put to other teams, such as those working with the elderly, with minority ethnic communities, with mental health users, and with people in residential homes. Other local organisations, including voluntary agencies, will have useful information also.

4.3 Training requirements

4.3.1 A useful response to the common plea "more training is needed" would be to determine who needs training, what needs to be taught, and who should be responsible for the work. In Rotherham, this was approached by conducting an audit of existing skills and expertise. A range of communication skills and knowledge was found within the sensory team and the staff of voluntary agencies providing services.

4.3.2 In deciding who needs training, you will need to distinguish between those workers needing specific skills, such as communicating and guiding, and the far greater number of staff needing awareness training about dual sensory disability. Where there are constraints of time and money it will be worth exploring ways of offering dual sensory loss training as part of other courses, rather than as a separate course.

WHAT SHOULD BE TAUGHT?

4.3.3 The overall aim of training is to inculcate in professional workers a sympathetic and understanding approach to people with dual sensory loss. This aim needs to be reflected and reinforced in every training opportunity. Training might include:

* what deafblindness means, who deafblind people are, and the impact of dual sensory loss on relationships and daily life,

* the impact of deafblindness on communication, the main factors influencing communication, and basic knowledge of the communication systems used,
the main principles of guiding a deafblind person,

the technical support available,

some of the basic principles involved in making assessments, and

services available to deafblind people, problems involved in accessing those services, information about law and disability, and key resources and organisations, both local and national.

4.3.4 Training needs to be underpinned by a clear message about the general principles that guide the department's work, and by the specific principles relating to work with deafblind people. These might relate to the importance of personal choice, of avoiding compartmentalising users' lives unhelpfully according to age and disability, and of not accepting sensory loss as a 'normal' part of ageing.

4.3.5 Training should also relate to ethnicity. People with dual sensory disability frequently experience various forms of discrimination. In addition, people from different ethnic backgrounds are likely to be subjected to a further level of discrimination because of prejudice about the colour of their skin, a lack of understanding of their specific cultural needs, and other effects of racism.

WHO SHOULD DO THE WORK?

4.3.6 Training can be provided in a variety of ways, and by a range of trainers; the important point is to determine clear objectives and a planned timetable for implementation. Priority should be given to having direct input from deafblind users and their carers and families.

TRAINING MATERIALS AVAILABLE

4.3.7 The CACDP resource pack Touch and Go (CACDP, 1994) contains material for trainers running the equivalent of ten two-hour sessions. It includes a video, briefings for each session, and worksheets and handouts for participants. The programme aims to teach proficiency in transmitting information to deafblind people, and leads to CACDP's Certificate in Communication and Guiding Skills with Deafblind People. The Certificate can be promoted as a public way of rewarding people for the time invested in training and for gaining new skills that will help the authority provide improved services.
4 DEVELOPING EXISTING SENSORY SERVICES

KEY QUESTIONS

1 Which organisations are involved in delivering specialist services to older deafblind people in your area? How do their responsibilities divide up? How are they funded? What arrangements help ensure they work together?

2 Are care staff provided routinely with awareness training about dual sensory loss? What procedures are there for ensuring that people are referred to the right worker?

3 Are registers kept up to date? Is there a formal process for cross-checking newly registered blind and partially sighted people with the deaf and hard of hearing register, and vice versa? Are people offered the opportunity for second or dual registration?

4 What benefits does registration bring to deafblind people?

5 What training courses are provided for specialist and non-specialist workers, and for non-professionals and volunteers, and what criteria are used for selecting those to be trained?

6 What do the training courses cover? Do they lead to a recognised qualification or endorsement?

7 What training is offered to, and given by, deafblind people and their carers? Do you include deafblind people from all the minority ethnic groups in your area?
"I've never had a doctor who could communicate with me, except for just 2 minutes in 1936."

"I started to go deaf and blind 10 years ago when I was 60. Now I'm completely deaf. I went to a day centre for 18 months but I couldn't communicate with anyone. Then a volunteer called Cliff taught me to talk and read, using the deafblind manual and braille. He took me to a rally one day with other deafblind people and I loved the contact with people there."

"They haven't a clue how hard it is in hospital for people like me. You could sit and cry with nothing to do and only the sounds of trolleys and heels going by to listen to."
5.1 Introduction

5.1.1 Deafblind people are not a homogenous group. Their individual needs are as varied as those of others in the community, and so it should be assumed that they will want access to the full range of available services. The key is how to provide general services in such a way that they are indeed as available to deafblind people as to others.

5.1.2 In wanting to provide well for deafblind people, you will be aiming at enabling them to gain fully from the services they use. The task is about achieving equity of outcome for all service users. Ensuring the best outcome for deafblind people will require additional resources, or available resources used differently; careful planning at each stage; consultation with deafblind users and their carers and families; and a willingness to take on board their views. The sensitive service you provide as a result of responding to the needs of this relatively small group of users is likely to have the added benefit of also improving the service you provide to other users.

5.1.3 The main issues to be considered when planning for deafblind people revolve around building and equipment design, the staff group and their training needs, and user participation.

5.1.4 BUILDING AND EQUIPMENT DESIGN It may be argued that the advantage of specialist accommodation for older deafblind people is that systems can be built in to make life easier for them. On the other hand, many already resident in homes will develop dual sensory loss over time, and all elderly residents are likely to benefit from surroundings where, for instance, glare is avoided, care is taken over design details such as contrasting colours for doors and jambs, and cups and saucers, and where background noise levels are kept low.

5.1.5 THE STAFF GROUP AND THEIR TRAINING NEEDS Guidance on deafblindness to residential staff should be viewed as a priority need, especially since people living in residential care are potentially more isolated than if they were living at home. Staff need to understand the particular complexities of deafblindness and be able to bring those to the attention of other residents.

5.1.6 Staff need to have communication and guiding skills, and be able to facilitate communication between residents or attendees at the day care centre. The skilled use of lipreading techniques and manual communication may be among the range of facilities required. They will also need to be alert to a person being unsure about how to use personal equipment, such as a hearing aid, and about when batteries need replacing and parts need adjusting.

5.1.7 Staffing levels should be such that the care of deafblind people is
not squeezed by the time demands of some other residents or users, such as those who need extra attention for their physical disabilities.

5.1.8 USER PARTICIPATION Good communication skills will enable staff to discover people's preferred ways of doing things. The special knowledge of carers, friends and relatives should be harnessed, too, and checked with the user if there appear to be conflicting views and opinions. Care plans should be made in meetings with users, and followed up by reviews and other ways of checking out user and carer satisfaction and suggestions.

5.2 Social welfare services

HOME CARE

5.2.1 Many older people who already have help in the home will find themselves affected gradually by dual sensory loss. It will be helpful if their home care assistant knows how to recognise sensory disabilities, and knows how to access specialist help for their client or can learn what is needed to provide some or all of that help themselves. Some authorities, such as Wigan (see Chapter 3) and Hertfordshire, offer specific training in deafblindness to suitably experienced home care staff. Others feel that deafblind people should be entitled to their own specialist Communicator-Guide or Guide-Help in order to play their full role as active citizens.

5.2.2 Inevitably, the availability of resources will be a factor in the decisions that are made. Hopefully, user choice will have its place, too. Whilst some people will welcome additional help from a familiar and trusted home care worker aware of the particular needs arising out of deafblindness, others may prefer to have a change in worker or to have access to a pool of different helpers for different activities.

DAY CARE

5.2.3 The pleasure of meeting others for shared meals and leisure activities, and of having a change from home surroundings, can be dampened by the obstacles that get in the way of easy movement and communication. Attention needs to be given to matters such as the transport arrangements to and from day care activities, the physical layout of places visited, and the arrangements for ensuring that deafblind people do not remain isolated - even though in company - because nobody is trying or succeeding in communicating well with them and integrating them into activities.

RESIDENTIAL CARE

5.2.4 Many older people will be able to continue living at home, even though they have serious sight and hearing loss, but other options may be preferred, or become necessary.
5.2.5 It is important to allow new residents plenty of time to settle in, to familiarise themselves with their new home, and to arrange their individual living space as they want it. A crucial part of this initial stage is encouraging people to maintain close links with carers, relatives and others who were part of their life at home.

EXAMPLE

* Suffolk SSD (see Appendix 2) has developed some basic indicators for good quality services for deafblind people living in a residential home. The guidelines are grouped into four significant areas: staff communication skills, the care plan and other written documentation, the environment, and social activities. Under each head are set out the responsibilities of assessors, home staff, the contract or service specification holder, and registration officers.

5.3 Health services

5.3.1 This section considers, first, those general matters that are likely to improve the quality of health services for deafblind people, and second, those aspects of service delivery that are relevant to particular parts of the health service.

GENERAL ISSUES ABOUT HEALTH SERVICES  (Many of these apply to social services too.)

RECOGNISING THE IMPORTANCE OF DUAL SENSORY LOSS

5.3.2 Recognising the importance of dual sensory loss is the crucial first step in providing services. That, in turn, can lead to proposals for joint commissioning between health and social services. A key appointment would be that of a policy co-ordinator, empowered to take responsibility for the development and implementation of a policy for services for deafblind people. The post holder would facilitate the crucial liaison between social services and health services – still poorly developed in many areas – that will enable deafblind people to be identified and recognised.

5.3.3 The policy co-ordinator would need to remain alert to new opportunities for pursuing funds to develop local initiatives, including the provision of community-based outlets for information and expert advice.

5.3.4 They will need to have an overview of training needs and an implementation strategy, including the development of joint training of health and social services staff. Procedures need to be established for reviewing progress towards service provision that is sensitive to deafblind users. An important element here is the development of procedures that enable staff to identify deafblindness early, and to respond quickly to people's needs. One
way of doing this is to build into assessment services for the elderly population a checklist that recognises the high incidence of sensory and dual sensory disability amongst older people.

PROVIDING AWARENESS TRAINING
5.3.5 All health staff should be trained in deafblind awareness, for the first step in providing appropriate services is an understanding of, and empathy with, the impact of dual sensory loss. Training is important for primary health care workers and specialists alike, for older people will benefit from a more flexible and sensitive approach at all levels of the service. This might be from hospital consultants who have deafblind awareness as well as some basic knowledge of communication systems; from chemists who take special care when dispensing prescriptions; and from health workers in the home, giving practical advice on hearing aids and batteries.

5.3.6 One model is for the policy co-ordinator to support one member of staff who undertakes to act as the point of reference for other health workers in their specialism. Part of their brief would be to ensure continuing awareness of deafblindness among other staff, and the induction of new workers.

DEVELOPING SENSITIVE SERVICES
5.3.7 Providing deafblind people with good information about services is an important first step. The information needs to cover general health services, including the right to complain. It should also highlight services of particular relevance to those who are deafblind, including the help that will be available during visits to clinics, surgeries and hospitals. Information should be in a variety of formats, such as braille, cassette, and videos with large and clear subtitles. Standard appointment letters and other written information is best produced in large print and plain language, whether English or translated.

5.3.8 Systems should be in place to facilitate a prompt and positive response from staff. Notes and files should be marked clearly to indicate that a patient is deafblind.

5.3.9 User-friendly systems of communication need to be in place also. Good sound and visual systems are needed in reception and waiting areas, but tactile systems are equally important. The personal touch is vital, to avoid people sitting anxiously, unsure whether they have been missed or forgotten. Giving occasional reassurance about how much longer they have to wait, and doing so by first touching the person and saying their name and yours, will be welcome indications of awareness and concern.

5.3.10 SPECIFIC MEASURES will be needed, too.
* The time allocated for appointments should be double that for other patients.

* Physiotherapy for the hands is a priority for those who use manual communication, and there should be consideration of how hands might be affected by things like intravenous and bruising injections.

* There should be screening of eyesight and hearing. An advantage of the early identification of hearing loss is that it allows older people time to adapt to a hearing aid.

* Particular care will be needed to inform deafblind people about diagnosis, about the outcome of tests, and about options for the future.

* Discharge plans will need to be geared to the user's individual circumstances, and developed as slowly as is necessary with users and those involved in their care.

* Transport needs to be thought of. The work of staff and helpers in this department, too, will be enhanced by deafblind awareness and knowledge of communication systems.

* Buildings and equipment need to be accessible. Level access, good light and contrast, tactile notices, quiet rooms for interviews, careful siting of loop and infra-red systems, and good acoustics in all areas are all important. Simple solutions can improve the environment dramatically for deafblind people. Their needs should be considered early on in the planning stage of new developments or modernisation programmes. It is cheaper to get these things right the first time rather than make adaptations later on.

PARTICULAR PARTS OF THE HEALTH SERVICE

5.3.11 GP SERVICES

* In view of their contact with so many people who are likely to develop dual sensory loss, GPs need to be alert to the particular issues facing deafblind people, and to the ways in which they can respond.

* Identification of dual sensory loss should be part of the hearing and vision check-up that GPs offer to those over 75. Before undertaking this hearing test GPs could check whether a BD8 form already exists for the patient and, if it does, they could highlight the need for a referral to social services. In addition, local authorities should notify GPs of older patients who become deafblind before their check-up at age 75.
5.3.12 VISUAL DISABILITY SERVICES (ophthalmology, low vision, eye clinics, optometrists)

* Staff at all levels should be aware of the importance of hearing loss. It should not be assumed that a patient wearing a hearing aid can hear normal speech; this may only be possible if there is little background noise.

* Consultants in eye clinics should be encouraged to link with social or information workers, to provide - where necessary - information and access to counselling.

* The BD8 form, with its section for noting 'significant hearing loss', should be used as a basis for cross referral, identification and assessment, especially between audiology and ophthalmology. It would be helpful for social services departments and health authorities to reach local agreement about a working definition of 'significant hearing loss' for this purpose.

* Optometrists should be encouraged to provide information about services, to recognise hearing loss, and to refer people to their GP for possible referral to a hearing aid clinic. Their location in high streets and shopping precincts leaves them well placed to offer this crucial service.

5.3.13 HEARING DISABILITY SERVICES (audiology, ENT clinics)

* Staff at all levels need to be aware of the importance of sight loss, and its likely impact when combined with hearing loss.

* Hearing therapists should help assess the effectiveness of a hearing aid that is prescribed, as aids for deafblind people need to be especially good.

5.3.14 HOSPITAL SERVICES (in-patient and out-patient)

* Extra help with personal care may be needed when patients prepare themselves for tests or a doctor's examination.

* Systems of allocating patients to nurses in hospital need to be flexible enough to avoid deafblind patients becoming frustrated by changes in staff teams that leave them suddenly - and often without notice - losing contact with staff whose voice and manner have become familiar. At the very least, a deafblind person in any hospital setting should have a named 'continuity person'.
Attention to apparently trivial matters will help deafblind patients retain their dignity and independence. Staff need to understand the importance of communicating with one another about things like the position of a person's locker and personal items and their preferred way of doing things. They need to be aware, also, that casual conversation as they move down the ward will exclude deafblind patients. They have to really stop and talk, and take time to communicate on a one-to-one basis.

5.4 Information about services

5.4.1 The importance of good communication systems and material has been raised already under different sections of the document. This section highlights some key general concerns for managers. They fall under two heads: those about giving information to users, and those about ways of encouraging users to give information to service providers. The role of advocacy is of particular relevance here.

GIVING INFORMATION TO USERS

5.4.2 The general rule is to invest from the start in the development of information and information systems that will be welcomed as user friendly by a wide spectrum of users.

5.4.3 There are many practical ways of offering deafblind people the same right of access to information as others have, and without their incurring extra costs or undue delay. For example, clear speech, and speaking at a gentle pace, is important, both in person and over the telephone. Background noise should be reduced as much as possible. Colour contrast is important for leaflets and other written material, and so is type size: at least 14 point (like this document) is recommended.

5.4.4 Signs and notices should be within easy reach - not more than 1.3 metres from ground level and in a position where they can be touched easily. They should be in raised bold capitals, between five and ten centimetres high, and in a simple, clear typeface. Free-standing boards and other signs that might be tripped over should not be used. The background of notices should be light in colour, with letters in black or another dark colour.

THE ROLE OF ADVOCACY

5.4.5 The power imbalance between an individual user and a service provider makes it imperative for local authorities to explore ways of making it possible for users to engage in discussions as more equal partners than clients have been traditionally. Users may benefit from an advocacy service to help them assert their wishes, and managers may need to encourage staff to see this as a positive way of empowering users to play a full part in planning
and decision making.

5.4.6 Training may be needed to help people grasp the essential elements of advocacy - that it is about helping someone work out what they would like to happen and then speaking up for them and helping them get their views taken seriously. It can be vitally important for users to have someone to argue their interest, to advise about what is being said or implied, and to suggest ways in which they might respond.

5.4.7 But advocacy services, too, are patchy at present. Authorities will need, therefore, to be pro-active about seeking out organisations who might be willing to extend to deafblind people their advocacy work with other user groups, and about encouraging the growth of new advocacy schemes.

5.5 Using Guide-Helps to access services

5.5.1 Most Guide-Helps expect to accompany users to their health care appointments. The benefits are obvious: the user is likely to be much reassured by the presence of a trusted companion at times that can be difficult for most people.

5.5.2 Guide-Helps can be of great assistance to users needing to visit or stay in hospital. Staff may fail to realise that someone is deafblind because they have learnt how to bluff their way through and so appear to react appropriately to questions and comments. Guide-Helps can alert staff and other visitors or patients to ways of communicating well with deafblind people. They can also make practical suggestions about ways of increasing the comfort and safety of deafblind patients and visitors. One health authority has encouraged the use of the sign "this patient has hearing and vision problems".

5.5.3 While the need for a Guide-Help will diminish for some people who move to residential care, others might continue to need help with journeys, activities, companionship, and preserving links with their ethnic community. Guide-Helps can also play a useful role in showing staff and other residents how to provide well for the particular needs of the person they are linked to.

5.6 Using interpreters to access services

5.6.1 Deafblind people who use deafblind manual or sign language, or an English signed system, or a spoken language other than English, may need or choose to communicate through an interpreter.

5.6.2 Like Communicator-Guides, interpreters provide ways of helping deafblind people break out of the isolation that stems from their dual sensory loss. The main difference is that whereas Communicator-Guides aid the
deafblind person in daily living, by offering communication and guiding support, the task of the interpreter is to convey faithfully the subject content, the mood of the situation, and visual, tonal and background information.

5.6.3 As with other matters, deafblind people should be offered as much choice as possible over who will interpret for them. Managers need to ensure that their staff know about, and have ready access to, interpreters with a range of communication skills, including British Sign Language and community languages. It needs to be recognised that, while there may be areas of the country with only a small or isolated population of black or other minority ethnic people, they may well want or need to use the services of social work agencies. Services should be provided to them according to expressed needs, not according to numerical proportions.

5.6.4 Budgets should enable staff to use trained interpreters, to ensure a high-quality service, especially in such formal situations as medical or legal consultations. Interpreters are professional people who maintain a strict code of confidentiality, and who are skilled in interpreting the sense and intent of what is said while preserving the content of interviews. The Sense document Making Contact contains useful information on interpreters (see Appendix 3 for this, and for useful contacts for interpreters).

5.6.5 However, since the availability of interpreters is patchy, people will often have to rely on friends or relatives. The goodwill and effectiveness of all these volunteer helpers can be bolstered by offering them training. CACDP's training resource packs Touch and Go and Interpreting for Deafblind People (Appendix 3) provide useful training material.
5 MAKING GENERAL SERVICES AVAILABLE TO DEAFBLIND USERS

KEY QUESTIONS

1. What proportion of staff in day care and home care services, and in residential establishments, have been trained to recognise sensory disability and are familiar with the different deafblind communication methods?

2. What steps are taken to ensure that deafblind people in residential establishments participate fully in the life of the home? Consider building design and equipment, and staff guidance and training.

3. What arrangements are in place to ensure liaison between specialist agencies and the general social and health care services needed by older deafblind people?

4. Are all staff trained to recognise that hearing and visual disability can interact to create a separate complex disability? How is this built into their training?

5. What information is provided about services for deafblind people, and in what media?

6. What advice, counselling and advocacy services are available to deafblind people and their carers and families?

7. What procedures have been established to provide deafblind people with easy access to interpreters and other communication support?

8. How might you use the Disability Discrimination Act 1995 to promote the interests of deafblind people?
"They think that because you're deafblind that you're dumb and you're daft."

"With the help of the red and white cane I was able to take a taxi to the shopping precinct, potter about, have coffee in my favourite bar. It was not much but it meant freedom, to do my own shopping. This independence only ended when the street was made too difficult."
6.1 Introduction

6.1.1 In providing well for deafblind users and their carers and families, authorities will be seeking to move away from the still all-too-precarious nature of current services to a service that is responsive to users' views of what is needed, and that strives for successful partnerships between interests and across sectors. Experience so far suggests that success in achieving these goals is likely to be enhanced by a strategic approach to several key and interlocking aspects of service planning, delivery and evaluation. Managers should guard against thinking that they need develop only one particular service for deafblind people, such as Guide-Helps or specialist assessment. Progress is needed on a full range of services. The key aspects of a strategic approach are set out below.

6.2 Service philosophy

6.2.1 A statement of the philosophy underpinning your service should act as a framework for the policies, procedures and practices that you develop. It should be drawn up with the collaboration of deafblind users and their carers and families, and of interested staff from your own and other agencies. It will need to be updated regularly in the light of experience and consultation.

EXAMPLE

* In Leicester, a Code of Practice for work with deafblind people has been endorsed by the local Dual Sensory Impaired Sub-Group, a group that includes representatives of various professional bodies, and service users and carers. The statement accepts and celebrates cultural diversity, condemns discrimination, adopts a 'whole person' approach, and forms a framework for the nature and quality of practice required of all organisations.

6.3 Keeping awareness on the agenda

6.3.1 The early work of awareness raising should continue. It needs to be aimed at new and existing staff at all levels, elected members, local organisations, and the general public.

6.3.2 This important work will provide opportunities for allaying some of the myths and fears that have hampered progress to date. So, dual sensory loss is seen, rightly, as a complex disability, but that should not deter people from explaining those complexities - it is not difficult to grasp the problems caused by deafblindness and to understand ways of tackling them successfully.

6.3.3 In addition, it is sometimes argued that only a handful of people are affected by the disability, but all the specialist services show that the need
is greater than is commonly thought. Nevertheless - and this is another fear - the resource implications for services need not be overwhelming. While some users will need a response that is resource intensive, the needs of most people will not require an expensive input.

6.3.4 The work of raising awareness should continue in a variety of ways, such as meetings, events and reports. Attention should be given to involving users in promoting awareness. Their contributions to training and education work are likely to present you with fresh insights into their needs and aspirations.

EXAMPLE

* Bradford SSD presented a report to its Disability and Community Health Sub-Committee eighteen months after the creation of a specialist post for deafblind people. The report identified the work done and the key issues arising, and led to an agreed agenda for future action. This included the recruitment and training of more sighted guides, the allocation of a specific budget for equipment and adaptations, and an increase in material (on tape and in community languages and braille) about eye conditions and services.

6.4 Identifying need

6.4.1 Statistics on deafblindness will never be complete, for there will always be people newly acquiring dual sensory loss, and others being newly identified even though they have been affected for some time.

6.5 Monitoring and evaluation

6.5.1 Nor will details and data be enough. It is important to assess the quality and efficiency of services, also, in order to plan the improvements that will help close the gap between the aims and achievements of service provision. A crucial part of this work is finding ways of testing user and carer satisfaction: you might use discussion groups, personal interviews, participation in conferences, and postal surveys.

6.5.2 Of particular importance will be what you ask and discover about communication systems - important because communication is a basic human right as well as a care need. It may be that your achievements will need to be followed up by other ways of aiding communication, in order to offer a range of people and methods. For example, while Guide-Helps may be liked and trusted, they might not be the best companion for all activities. Independent advice and advocacy might be a better way of catering for some needs.

EXAMPLE
Wigan SSD sent out a large-print questionnaire to people who had been visited by the Sensory Impairment Team. The cover note from the team leader invited users to get a relative or friend to help them fill it in. The questions are headed "How well did we do?". They ask about the manner, appearance and punctuality of staff, the length of the visit, the clarity of explanations given, and the extent to which needs have been met. Boxes are ticked on a four-point scale, from poor to excellent. Suggestions for improving the service are also invited.

6.5.3 A commitment to publishing the findings of evaluation work will give people the chance to judge for themselves how well you are doing.

6.5.4 Valuable information will emerge, too, from your local authority complaints procedure. The procedure itself, and the way in which complaints are dealt with, need to reassure all users - including those who are deafblind - that their views and comments will be taken seriously and dealt with swiftly and fairly.

6.6 Staff support and development

6.6.1 Staff who are supported and supervised well themselves are likely to be more confident in the support they offer to users. Managers need to remain responsive to suggestions for improved practice that spring from the direct work with users.

6.6.2 Opportunities will be needed for specialist workers to meet their counterparts in other areas, not just because many are new to their job and perhaps anxious about the range of their responsibilities, but also because meeting like-minded colleagues can be an enormous boost to energy and commitment.

6.7 Gaining public commitment to services

6.7.1 Part of this strategy is about finding ways of involving other agencies in your service development. This might include setting priorities jointly with the health authority, and liaising well with different strands of the health service. For example, Bradford have held discussions with consultants about the quality of the BD8 form, and they have also organised 'eye days' with GPs. Camden and Islington Health Authority have concentrated on building on the services provided by optometrists (see Appendix 2).

6.7.2 Another part of the strategy is about generating a corporate sense of responsibility about services for deafblind people. There may be a need to encourage other departmental managers - in housing, education, finance and information sections - to review their systems periodically, to ensure that
deafblind people are able to gain equal access to all local authority services.

6.7.3 A third aspect relates to getting and keeping current services and future plans in the public arena. Clear and specific commitments in the Community Care Plan for services will bear witness to your achievements, and will help keep alive your hopes for future action. Local newspapers and other media can help do the same thing.

6.8 Resources

6.8.1 Opportunities will need to be sought and seized for influencing purse holders, and knowledge will be needed of the deadlines for submitting new and different sorts of bids. Having to hand updated costings on a range of specific future developments can be a useful way of not missing the chance to convert wishes into reality.
KEY QUESTIONS

1. How does the local authority demonstrate its commitment to meeting the needs of older deafblind people – in planning services, describing services, delivering services, ensuring access to services, and ensuring access to the complaints procedure?

2. What quality assurance methods have you developed for work with older deafblind people? Does the health authority use similar methods?

3. Are your mainstream services attractive to deafblind people from local ethnic minority groups? Is information available in their first language?

4. How do you measure the quality and appropriateness of your training?

5. What budget is allocated this year and next for services for deafblind people, and what percentage is allocated for equipment, grants to voluntary organisations, agency agreements, residential care, alternative community care packages, training, and other heads? How is the budget allocated and monitored?
The following case studies highlight the variety of needs and circumstances experienced by older deafblind people, and the range of responses that can best support their communication, information and mobility needs. The stories serve as a reminder that dual sensory loss affects people in different ways, that deafblind people will also have other physical health – and possibly mental health – needs, and that one particular service will not suit everyone. The best outcomes will result from a flexible approach, and a combined package of services that are well co-ordinated and that draw on the strengths of the voluntary and community sector as well as statutory agencies.

1 MRS A - AGED 84 - LIVES AT HOME

Mrs A lives alone in a rented ground floor flat. She was born profoundly deaf and uses BSL to communicate. In the past she was an active member of the Deaf community. Over recent years she has developed glaucoma, resulting in loss of vision in one eye and partial sight in the other.

In 1991 both her husband and brother died. Mrs A had had little contact with social services and was mostly dependent on her friends from the Deaf club to support her through this traumatic period. Her social worker at that time recognised signs of mental illness as Mrs A began to express paranoid ideas about a member of her family whom she had not seen for years. Additionally, she began to neglect herself and show signs of withdrawal. This decline in her mental health was accompanied by a general physical deterioration and concerns that her vision was getting worse. In view of the impact of her vision on communication and mobility it was agreed that the case should be transferred to the social worker with deafblind people.

Mrs A's GP was unresponsive to concerns expressed repeatedly about her mental health, possibly through lack of understanding of her sensory loss. It was agreed, therefore, that Mrs A should be referred directly to the Deaf Psychiatric Service at a nearby hospital. Following assessment by a psychiatrist competent in Sign Language, Mrs A was diagnosed as having a psychotic illness, probably triggered by her bereavements and the isolating effects of her now dual sensory loss. She was prescribed medication and received counselling in her preferred language, BSL, from a community psychiatric nurse.

Meanwhile, further assessments were carried out by the occupational therapists and rehabilitation workers who contributed to a care package which also included regular home care provision and the home meals service.
Mrs A had expressed a strong wish to continue living in the community, yet a combination of her dual sensory loss and the deterioration in her mental health left her unable to access mainstream services and at risk of becoming further isolated. As a result, it was agreed that Mrs A be offered a weekly visit by a Guide-Communicator. The service offered Mrs A the opportunity to maintain control over her life, by enabling her to undertake a range of activities independently, such as managing correspondence, visiting the dentist, taking the cat to the vet, and shopping for clothes. An additional and vital component has been the befriending aspect of the service.

Mrs A's situation has now stabilised and there has been a considerable improvement in her mental health. The Guide-Communicator service has provided the foundation for a complex package of care, without which it is probable that Mrs A would not have been able to continue living in the community.

2 MRS B - AGED 98 - LIVES IN RESIDENTIAL CARE

Mrs B is profoundly deaf, with limited residual vision. She communicates using the Deafblind Manual. Until two years ago she was living alone in the community, reluctant to accept anything other than a minimal level of support from social services.

She was extremely concerned that her independence be maintained. She greatly appreciated social contact, both through the local deafblind club and through a network of friends who visited her at home. But she perceived the offer of any additional support, particularly of a practical nature, as a threat to her independence. So, at the age of 96, despite concerns about her safety, Mrs B continued to cook for herself and manage her own personal care.

Early in 1994 Mrs B attended a consultation meeting to discuss the establishment of a Guide-Communicator service in the borough, and a little later she was offered Guide-Communicator support, to supplement her existing care package and to help maintain contact with her social network.

The service was introduced and monitored carefully, and it rapidly became apparent that Mrs B viewed the worker as a professional befriender who represented an unwelcome threat to her independence. Her response was similar to her attitude to representatives from other agencies, particularly the medical profession - she had extremely low expectations and could not accept the concept of a service that sought to increase her range of choice and opportunity. It was agreed that a regular Guide-Communicator was not appropriate but that the service would be available to Mrs B if she wished to use it in the future.
At around this time Mrs B developed leg ulcers, and much gentle persuasion was needed to get her to agree to see a doctor. Reluctantly, she allowed the community nurse to visit her several times a week to dress the ulcers. The nurses were trained to use the Deafblind Manual and, over time, Mrs B not only began to trust them but also to look forward to their visits. This resulted in a more general acceptance of other services, such as the chiropodist and meals on wheels. Where possible, her social worker for deafblind people accompanied any new worker on their first visit and offered basic communication training.

Later that year Mrs B had two falls at home when on her own. Although not hurt badly, she recognised her own feelings of vulnerability and, now aged 97, asked to go into residential care. A small residential care home for elderly deaf people was identified - it offered an environment where staff had appropriate communication skills and from where Mrs B is able to maintain links with her social network.

Mrs B has adapted well to residential care. She rapidly came to accept support with the practical aspects of her care. Although mildly confused, she remains very articulate, with the ability to make informed choices. She has obviously benefitted immensely from being in an environment where there is a focus on residents' communication needs. Far from withdrawing, she has become more confident and outgoing.

3  MRS C - AGED 86 - LIVES AT HOME

Mrs C was born with a severe visual disability. She is now totally blind and has also developed a severe hearing loss. She lives alone on the ground floor of a high-rise block of flats.

Mrs C has used an aid behind the ear for many years, but there has been a gradual but now significant deterioration in both her hearing and her ability to manage her aids herself. She learned the Deafblind Manual but prefers not to use it.

However, Mrs C has led a full life as an extremely independent blind person. Her gregarious nature helps to convey the impression - often true - of a brave, blind, cheerful old lady, and this gains her attention, respect and status. It is an image in which she participates fully and cultivates. Nevertheless, this perceived image is an important part of her coping strategy and underpins a fragile balance.

Mrs C is supported in the community by a complex network:

*  Although there have been changes in neighbours and the death of
particular friends, the caretaker and other people in the flats keep an eye on her. Two of her three children keep in regular contact although are not able to provide practical support. She is still able to use the phone and has the confidence to do so, although receiving information is difficult for her.

* She has twice-weekly visits from home care workers, trained generally in deafblind awareness and skilled for Mrs C's individual requirements. She has a weekly visit from a long-term Guide-Help, and she had two other Guide-Helps who visited regularly for a year and accompanied her to a local drop-in centre.

* Until a year ago, Mrs C was an active member of the Deafblind League, attending meetings and going on holidays and outings. She still attends the local blind society social group for half a day a week.

* She goes to a day care centre twice a week and, when she wants to, is taken to church on Sundays and enjoys regular visits from a young church member who takes her out occasionally.

* Mrs C has participated in the training programmes of her local Sensory Disability Team.

Many other mainstream services have been involved in her care, including housing, chiropody, district nurses, pharmacy, and residential respite care. Her GP is very responsive, and the audiology service, in particular, fully recognises the implications of her dual sensory loss and has appreciated the additional complications of her frailty and her deteriorating physical abilities.

The Sensory Disability Team has been able to co-ordinate input from all the services, and remain a key contact for each, but Mrs C has great determination and continues to make choices and direct her own take-up of services and resources. Her perceived needs and preferred options have informed the comprehensive assessment of her needs and helped produce a care plan with clear aims and objectives.

In this case, the mainstream services do not require highly specialised workers to provide what is needed. The key specialist worker liaises with a complex network of professional and voluntary services, monitoring and evaluating services and changing circumstances, and managing the risk of supporting Mrs C as she lives alone in the community.
APPENDIX 2

THE PILOT WORK OF LOCAL AUTHORITIES AND HEALTH AUTHORITIES

* BRADFORD, CITY OF - SOCIAL SERVICES DEPARTMENT

Contact  Peter Kay, Manager (Disabilities), Bingley Area Office, Town Hall, Myrtle Park, Bingley BD16 2LQ.
Tel: 01274 758700. Fax: 01274 510348.

In conjunction with Sense, Bradford developed an information pack, and held training awareness days for the staff of residential and nursing homes and long-stay hospital wards. A survey of residents in these establishments helped to identify 90 older deafblind people. Bradford are now undertaking specialist assessments of their needs that arise from their dual sensory loss. A report of the survey highlights the main findings, and the difficulties encountered in this type of exercise.

Bradford has also developed a Guide Support scheme to provide practical help and support to people with dual sensory loss. A strategy for meeting the needs of older people with dual sensory loss has been drawn up, and relevant targets are included in the Community Care Plan.

Information available  Committee reports to elected members; strategy for working with older deafblind people; information pack; leaflets; training pack; survey report on older people with dual sensory loss in institutional care; deafblind social worker job description and personnel specification; various papers about the new Guide Support Scheme.

* BROMLEY, LONDON BOROUGH OF, BROMLEY VOLUNTARY FORUMS, BROMLEY HEALTH - Joint Commissioning

Contact  Carol Infanti, Disability Database Manager, Joint Commissioning, Civic Centre, Stockwell Close, Bromley BR1 3HU.
Tel: 0181 313 4626.

Bromley commissioned the Deafblind UK (formerly the National Deafblind League) to conduct a survey of local residents known to have dual sensory loss. The aim was to research the needs of deafblind people and find out whether they were receiving the services they needed in order to be as independent as possible. A semi-structured interview was used, covering mobility, transport, communication, accommodation, equipment, information, care and support, health, finances, and activities/opportunities. The findings of the study and
recommendations in the report will assist in developing an action plan. Follow-up action included a joint, half-day awareness training programme.

* CAMBRIDGESHIRE COUNTY COUNCIL - SOCIAL SERVICES DEPARTMENT

Contact Derrick Biggs, Service Manager Disability, 1st Floor, Sundance House, Staniland Way, Werrington, Peterborough PE4 6WR.
Tel: 01733 57167. Fax: 01733 328681.

The SSD conducted a survey of deafblind clients, inviting comments on the Guide-Help Service and other social services, and on community and hospital health services. It also distributed an information pack and questionnaire about services to a wide range of establishments. A steering group included service users and voluntary organisations, as well as Health Authority and SSD staff. The work aimed to identify good practice, raise professional awareness, and help agencies modify and extend their services to deafblind people.

Information available Interview framework and report on the user survey; awareness raising questionnaire survey of facilities for deafblind people, and the report on its findings.

* CAMDEN AND ISLINGTON HEALTH AUTHORITY

Contact William Vineall, Ophthalmic Services Commissioner, Hobson House, 155 Gower Street, London WC1E 6BH.
Tel: 0171 383 4155. Fax: 0171 383 4720.

As part of the low vision service from optometrists' practices, it was decided to identify how many people with low vision had a hearing disability also. The optometrists are trained in audiology awareness and, since November 1996, offer a questionnaire on hearing to each patient who attends for a low vision assessment. If it is thought necessary, patients are advised to have an audiology check at the Royal National Throat Nose and Ear Hospital. A parallel service has been set up in which a low vision assessment form has been given to each hospital patient attending for an audiology out-patient appointment. Patients's records are matched, and the completed form from each service is sent to the Health Authority, to record the number of people with both a sight and hearing disability.

Information available Questionnaires
Essex SSD has produced a physical and sensory needs survey and a profile of service users with dual sensory impairment in Mid-Essex. As a result of this information, the SSD commissioned a research report from the RNIB to establish more accurately the number and needs of local deafblind people. The findings will lead to an action plan.

Information available
The reports

Hampshire SSD has also recognised the need for a Commissioning Officer at Headquarters, to take responsibility for service planning in the County.

Leicestershire SSD has produced a research project to identify the prevalence and needs of dual sensory disabled people and their carers in the county. The final report, Enforced Isolation by Beryl Palmer, is now available. The research was endorsed by a Multi-Agency Support Group, with advice on methodology provided by Loughborough University. The project combined local research and an international perspective.
Following the project the Society launched a recruitment programme through the local press in order to provide a Befriending Scheme using volunteers. It enlisted the help of a dual sensory impaired person who explained how a volunteer could help a person with dual sensory impairment regain some independence. The Society has set up a training programme, covering hearing and sight loss awareness, guiding skills, communication skills, monitoring and supervision, confidentiality, and health and safety issues.

Through a Service Level Agreement with the local authority SSD, the Society now employs three paid Guide Helpers, each working 20 hours per week. They have received extensive training and provide a comprehensive guide help service to nine dual sensory impaired people. This scheme runs in parallel with the volunteer scheme.

Information available: Guide Help Scheme service specification; Guide Helper job description; Role of the Guide Helper; training programme; statement on charging policy; commissioned document into the Guide Help Scheme, Code of Practice; Enforced Isolation report.

* Rotherham Metropolitan Borough Council - Social Services Department

Contact: Jill Jones, Care Manager of Sensory Disabilities Services, Crinoline House, Effingham Square, Rotherham, South Yorkshire S60 1AJ.
Tel: 01709 822354 (text). Fax: 01709 822317.

Rotherham SSD set up a Working Party to explore ways of identifying more deafblind older people in their area. A screening form was devised, drawing on the Think Dual Sensory draft guidelines. The response highlighted the lack of specialist expertise among practitioners, and the particular problems of consulting deafblind users. Proposals resulting from this exercise include a Guide/Communicator Scheme, a separate computer code to identify deafblind people, the development of a service strategy in consultation with users, training for staff, and the recruitment of dedicated workers with interest and/or expertise in dual sensory loss.

* Salford, City of - Social Services Department

Contact: Nick Erlich, Community Manager, Sensory Disability Service, Sensory Disability Team, 11 Irwell Place, Eccles M30 0FN.
Tel: 0161 789 7331 (voice), 0161 707 7225 (minicom only). Fax: 0161 707 9519.

Salford SSD has presented the Think Dual Sensory definition of deafblindness to all interested statutory and voluntary organisations in the area. The
definition is seen as broad-based enough to cover all aspects of provision, and has been accepted by the Directorate of Social Services, Community Managers from Social Services, Salford Royal Hospitals NHS Trust, Salford's Community Services NHS Trust, Salford Health Promotion Centre, the Jewish Blind Association of Manchester, and Henshaws Society for the Blind in Manchester. The Hospital Trust has also agreed to include the definition in its Patient Charter.

A protocol for the care of people who use their hands for communication has been adopted by Salford Royal Hospitals NHS Trust. It aims to bring the special needs of deafblind and deaf and blind people to the attention of medical and nursing staff.

Information available  Protocol

* SOMERSET COUNTY COUNCIL - SOCIAL SERVICES DEPARTMENT

Contact  Nyree Bevan, Service Manager - Disability and Sensory Loss, Halcon Social Care Centre, Huish Close, Taunton, Somerset TA1 2EP.
Tel: 01823 338781. Fax: 01823 325410.

Somerset selected two areas of work for research and investigation: the identification of deafblind people with mental health problems, and user consultation. A survey was conducted to try and gauge the incidence of mental health problems among elderly deafblind people. Recommendations included the need to encourage and enable more sensory loss workers to be trained to Approved Social Worker level, and the need to raise the profile of dual sensory loss awareness training for all providers of residential services. A small questionnaire survey of deafblind people helped identify services and information received, gaps in current provision, and ways of consulting users more widely. The results have helped in the production of consultation forms for next year.

Information available  (in all forms, on request, from Signpost, tel: 0800 317220 or 01823 255170) Somerset County Care Plan 95/96, and draft 97/98; Changing Focus - Handbook for People with Visual Impairment; Earmark - Handbook for People with Hearing Impairment; Feeling Bad, Feeling Better - video discussion, in BSL, of mental health problems; Lip Reading Classes.

Survey to identify people with dual sensory loss (Somerset CC 1991); Survey of people with hearing impairment (Somerset CC 1991); Review of services for people with sensory impairment (Somerset CC 1992), Survey to identify people with dual sensory impairment (Somerset CC 1994).
The work of the pilot group has helped identify key areas for future development. These include the employment of dedicated dual sensory loss workers; training for Assessors, Registration Officers and care staff – the latter using NVQ-style competencies; a guide-communicator pilot project; and revision of the purchasing specification for residential and nursing homes.

Information available Various reports on the work of the pilot group; good practice guidelines for residential homes.

* WANDSWORTH, London Borough of - SOCIAL SERVICES DEPARTMENT

Wandsworth provided case studies which enabled the pilot group to explore many aspects of services to deafblind people, including the overlap between health and social services, the need to avoid stereotyping deafblind people, and the range of services needed to offer individual packages of care.

Information available Guide-Communicator service - Guide-Communicator job description; person specification; service specification; report on the one-year pilot project. Deafblind manager post - job description. Information booklets - information for people who are blind, partially sighted, deafblind (available in large print, braille, and tape); information for people who are deaf, hard of hearing, deafblind.

* Wigan, Metropolitan Borough of - SOCIAL SERVICES DEPARTMENT

Wigan Sensory Disability Team continues to develop their existing practices, with a renewed focus on collaborative working. The aims are to refocus awareness training; promote clear lines of communication; develop responsive practice and service delivery; and ensure accessibility for users, carers and
colleagues by a clear identity and widespread distribution of information.

Outcomes achieved so far include the recognition of the sensory disability team as the lead service for sensory referrals for Wigan and Leigh; regular sensory disability workshops presented by the team as joint training for staff of the SSD, Health Trusts and FHSAs; outreach work with audiology and technical staff to identify dual sensory loss; a presentation and follow-up to representatives of the SSD, DHA, and Registered Proprietors and Managers of Nursing Homes; and awareness training through corporate customer care.
APPENDIX 3

PUBLICATIONS, RESOURCES AND CONTACTS

* PUBLICATIONS AND OTHER MATERIAL

Breaking Through - Developing Services for Deafblind People (1988) Deafblind Services Liaison Group

Sign Posts - Leading to Better Social Services for Deafblind People (1989) Social Services Inspectorate, Department of Health

Good Sense Guide (1991) Social Services Inspectorate, Department of Health

Needs Survey (1991) RNIB (address below)

Touch and Go - Developing skills in communicating with deafblind people (Second edition, 1994) The Council for the Advancement of Communication with Deaf People (CACDP) (address below)

Silent Horizons (1994) Bristol Royal Society for the Blind, Stillhouse Lane, Bedminster, Bristol BS3 4EB

Interpreting for deafblind people (1995) The Council for the Advancement of Communication with Deaf People (CACDP) (address below)

Making Contact: How to Involve and Communicate with a Deafblind Person (1996) Sense (address below)


Enforced Isolation (1996) Leicestershire Society for the Blind, Margaret Road, off Gwendolen Road, Leicester LE5 5FU

Making Sense - a video-based training pack on sensory loss, for senior managers (1997) Social Services Inspectorate, Department of Health
RESOURCES AND CONTACTS

Making Contact (above) contains information on consultation and communication methods used by deafblind people, and explains how to book an interpreter.

For a list of interpreters, contact:

The Council for the Advancement of Communication with Deaf People (CACDP)
Pelaw House
School of Education
University of Durham
Durham DH1 1TA
Tel: 0191 374 3607 (voice, text, minicom)

The following organisations work to promote the needs of, and services for, deafblind people. Each provides a range of consultancy and other services both directly to deafblind people and to agencies that seek to meet their needs.

DEAFBLIND UK
100 Bridge Street
Peterborough PE1 1DY
Tel: 01733 358100
Fax: 01733 358356

BRITISH DEAF ASSOCIATION (BDA)
1 Worship Street
London EC2A 2AB
Tel: 0171 588 3520
Fax: 0171 588 3527

ROYAL NATIONAL INSTITUTE FOR THE BLIND (RNIB)
224 Great Portland Street
London
W1N 6AA
Tel: 0171 388 1266
Fax: 0171 388 2034

ROYAL NATIONAL INSTITUTE FOR THE DEAF (RNID)
19-23 Featherstone Street
London EC1Y 8SL
Tel: 0171 296 8000
Fax: 0171 296 8199

SENSE
11-13 Clifton Terrace
Finsbury Park
London N4 3SR
Tel: 0171 272 7774
Fax: 0171 272 6012
APPENDIX 4

JOB DESCRIPTION FOR A DEAFBLIND COMMUNICATOR-GUIDE OR GUIDE-HELP

Main Purpose
Through the provision of communication support and escorting, to enable deafblind and dual sensory impaired people to have greater independence and a better quality of life.

MAIN TASKS AND RESPONSIBILITIES
1. At all times to act as the eyes and ears of the service user – relaying what is seen and heard, including all spoken contributions, non-verbal and environmental information. This will include, among other things, indicating who is and is not present, people’s appearance, facial expression/body language, what is happening around them, and the weather.

2. To visit service users at home to provide access to correspondence and other written information, assist with letter writing, filling out bills/cheques, and making telephone calls.

3. To escort service users (on foot or by private or public transport) outside the home, on shopping and other activities, to clubs, and on other recreational activities of the service user’s choice.

4. To act as companion to the service user, providing access to news, information and other services of the user’s choice.

5. At the request of the service user, to assist with – or make arrangements for – appointments, visits, holidays and other activities of the service user’s choice.

6. To provide the service user with access to the above activities and services through the effective use of good communication skills, which may include deafblind fingerspelling, the block alphabet, clear speech and other means of receptive and expressive communication, as required to meet their individual needs.

Appendix 4

JOB DESCRIPTION FOR A DEAFBLIND COMMUNICATOR-GUIDE OR GUIDE-HELP

7. When communicating with, or interpreting for, the service user, to support and facilitate their wish or ability to use any hearing or sight they may have.
Examples include:
a speaking clearly and reducing background noise to enable a hard-of-hearing person to hear, and
b enabling a person to lipread by using clear lip patterns and identifying/making use of appropriate lighting.

8 To maintain a daily record of work and activities undertaken.

9 To respect and maintain the service user’s right to privacy and confidentiality at all times.

10 In the event of an emergency, to take responsibility for summoning help and taking other necessary action, within the limits of the training provided.

11 To attend supervision sessions with the Service Co-ordinator.

12 To book interpreters, with the appropriate interpreting skills, as required by the service user.

13 To provide cover for other Communication-Guides (or Guide-Helps) as required.

14 To undertake any other duties commensurate with the post.

15 At all times, to carry out their responsibilities with an understanding and a commitment to the organisation’s Equal Opportunities policy.
APPENDIX 5

SCREENING SHEET FOR AN INDIVIDUAL WITH BOTH POOR VISION AND HEARING DIFFICULTIES

Please complete all sections on this form

Your Name:

Job Title:

Agency and Address:

Telephone No: Date:

Name of Individual:

Address:
First Three Letters of Surname □□□ For office Use Only

Date of Birth: □ Age: □

Gender: □ Male □ Female

White □ Asian □ Black/Caribbean □ Black African □


Black other (please specify) □ Other (Please Specify) □

Name of School
(if under nineteen years of age)

Yes □ No □ Not Known □

Lives Alone □ Yes □ No □ Not Known □

Lives permanently in Residential Care □ Yes □ No □ Not Known □

(Eg residential home, nursing home, group home etc.)

Learning Difficulties □ Yes □ No □ Not Known □

Has learning difficulties (previously known as mental handicap)

APPENDIX 5

SCREENING SHEET FOR AN INDIVIDUAL WITH BOTH POOR VISION AND HEARING DIFFICULTIES

Visual Difficulties (Tick 1 box only) For office Use only

Please tick if in your opinion, the individual....

Has severe visual difficulties (or is registered blind) □

For example: cannot see well enough to recognise a friend who is an arm’s length away.
Has moderate visual difficulties (or is registered partially sighted)
For example: cannot see well enough to recognise a friend across a room.

Uncertain but "Acts as if" having visual difficulties
For example: some individuals who have severe learning difficulties or who have experienced strokes etc.

Hearing Difficulties (Tick 1 box only)
Please tick if in your opinion, the individual...

Has profound/severe hearing difficulties
(or is registered deaf with/without speech)
For example: has difficulty hearing someone talking in a loud voice in a quiet room, even if wearing a hearing aid.

Has moderate hearing difficulties
(or is registered hard of hearing)
For example: with or without aids, has difficulty hearing someone talking in a normal voice in a quiet room.

Uncertain but "Acts as if" having hearing difficulties
For example: some individuals who have severe learning difficulties or who have experienced strokes etc.

APPENDIX 5

SCREENING SHEET FOR AN INDIVIDUAL WITH BOTH POOR VISION AND HEARING DIFFICULTIES

<table>
<thead>
<tr>
<th>Hearing Aid</th>
<th>Yes</th>
<th>No</th>
<th>Not Known</th>
<th>For Office Use Only</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wears a hearing aid</td>
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<td>□</td>
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<table>
<thead>
<tr>
<th>Speech Difficulties</th>
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<tbody>
<tr>
<td>Has speech difficulties or no speech</td>
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<table>
<thead>
<tr>
<th>Communication</th>
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<th>No</th>
<th>Not Known</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>
Communication by sign language or the use of hands eg BSL, Makaton, home made signs etc.

*If yes, please specify*

<table>
<thead>
<tr>
<th>Time of Onset</th>
<th>Yes</th>
<th>No</th>
<th>Not Known</th>
</tr>
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<tbody>
<tr>
<td>Born with visual difficulties</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Born with hearing difficulties</th>
<th>Yes</th>
<th>No</th>
<th>Not Known</th>
</tr>
</thead>
</table>

Please return ALL sheets to:

To be completed by the Project Worker

- Registered Blind
- Partially sighted
- Deaf without speech
- Deaf with speech
- Hard of hearing