Enforced isolation: a study of the needs of dual sensory impaired people living in Leicestershire

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ENFORCED ISOLATION: A STUDY OF THE NEEDS OF DUAL SENSORY IMPAIRED PEOPLE LIVING IN LEICESTERSHIRE

by

Beryl Helen Palmer

A Masters Thesis
Submitted in partial fulfilment of the requirements for the award of Master of Philosophy of Loughborough University

December 1998

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DEDICATION

This report is dedicated to all dual sensory impaired people.
ABSTRACT

In 1989, a report entitled Breaking Through highlighted the failure of Local Authorities to address the needs of deafblind people, about whom little is known. This study aimed to identify dual sensory impaired people in Leicestershire, and to examine the needs of adults and older dual sensory impaired people in the light of existing theory, knowledge, policy and service provision. A two stage approach was adopted. The first stage comprised of a quantitative survey; a screening sheet was devised to identify individuals and widely distributed amongst local statutory and voluntary agencies and advertised to the public. A total of 1462 people were identified. This figure is equivalent to 169 per 100,000, over four times higher than earlier local studies had found. The majority were over 75 years of age, adventitiously impaired and relied on residual hearing and sight for communication. These findings challenge the stereotype of a deafblind person and point to changes in epidemiology in recent years. The second stage comprised of a qualitative survey of 24 adults and older dual sensory impaired people. Interviewees were asked about their daily difficulties and about their use of health and social care services. They were found to be an extremely heterogeneous group with very varied life experiences and situations. However several common themes emerged including the need for improved access to information, employment (for adults), education, social and leisure activities, and general community facilities. Some experienced lives devoid of meaningful activity and quite severe isolation. They were disadvantaged by the medical model and single sensory approach of health and social care service providers. On the basis of the findings a series of suggestions to improve current health and social care service provision were made. These included improvements to mainstream services such as adopting an empowering approach, recognising the existence of dual sensory impaired people, undertaking health promotion work, adopting a care management approach, undertaking staff training, improving co-ordination, and ensuring access to all services. In addition, the need to develop some specialist local resources was identified.
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CHAPTER ONE

THE BACKGROUND TO THE STUDY
WHAT IS DUAL SENSORY IMPAIRMENT?

The majority of the information that the brain receives comes through the senses of hearing and sight. The impairment of either sense will clearly have significant consequences for the individual, and people try to compensate as far as possible in such circumstances. For example, hearing impaired people compensate for their lack of hearing by using their sight to assist communication, perhaps by using sign language or lip-reading and watching for visual clues. Visually impaired people rely on their hearing to localise sounds and orientate themselves in their environment.

For a person with a dual sensory impairment, however, compensation is not an option. In addition, dual sensory impairments are said to be synergistic. That is, a visual impairment will multiply the effects of a hearing impairment, making communication much more difficult, and a hearing impairment will multiply the effects of a visual impairment, making mobility much more difficult.

McInnes and Treffy (1982) state:

"The deafblind child is not a deaf child who cannot see, or a blind child who cannot hear. The problem is not an additive one of deafness plus blindness. Nor is it solely one of communication or perception. It encompasses all these things and more. The deafblind are multi-sensory deprived. They are unable to utilise their distance senses of vision and hearing to receive undistorted information."

The effects of dual sensory impairment create difficulties in communication, gaining access to information and mobility. Of these, communication is perhaps the most critical. As Wolf et al., (1982) stated:

"Throughout the literature, communication is identified as the greatest problem facing any deaf-blind person."

The communication methods used by dual sensory impaired people are extremely varied, and are determined largely by the time of onset of their impairment(s), their ordering and their severity.

Generally, people will continue to use the method of communication with which they were familiar prior to the development of their impairment(s), if this is at all possible. For example, many people may be able to continue to communicate by making maximum use of their residual vision and hearing, by lip-reading and/or listening and speaking; profoundly Deaf people with an acquired visual impairment may be able to continue to use British Sign Language (a language where signs are used for words or phrases or descriptions). They may use some specific techniques such as "tracking", whereby the individual holds onto the hands of the signer to keep them in their field of vision; or the "hands-on" method, whereby the dual sensory impaired person places his or her hands on top of the hands of the person signing.
For some visually impaired people who acquire a hearing impairment, Braille, Moon or large print previously used as a written form of communication may increase in importance, and for some may become a major method of communication with others. Congenitally dual sensory impaired people may communicate by using very simple signs, or a sign system such as Makaton, or tactile symbols. Some people who develop a dual sensory impairment in later life may continue to make maximum use of their remaining sight and hearing and may find hearing and low vision aids helpful. Some people with severe impairments may use the tactile deafblind manual, where letter symbols are spelt out by the speaker on the hand of the disabled person.

Poor communication, coupled with restricted access to information and limited mobility can lead to isolation. Various studies and reports have highlighted the severe lack of stimulation and extreme isolation experienced by some dual sensory impaired people. This can have damaging consequences for their mental health and well being.

"Deafblindness is an isolating disability which effectively cuts communication with the immediate environment and the wider world beyond." (Deafblind Services Liaison Group, 1988)

One sensory loss is enough to make most people cut off but the double loss creates isolation of a different magnitude. The combination of limitations in conversation, loss of friends, limited access to information from the media, and difficulty manipulating the physical environment combine to create a very intense feeling of isolation." (Luey, Belser and Glass, 1989)

"Because of the barriers imposed deafblind persons are usually isolated and are often excluded from activities which are occurring in their environment." (Wolf et al., 1982)

This study will argue that people with varying degrees of combined vision and hearing impairments are disabled by society's failure to meet their needs, rather than by the impairments themselves.

WHO ARE DUAL SENSORY IMPAIRED PEOPLE?

When thinking about dual sensory impaired people, there is a tendency to think only in terms of the cultural stereotype of a deafblind person, who is believed to neither see nor hear anything. In fact, the number of people who experience total deafness and total blindness is extremely small; the majority of dual sensory impaired people have residual sight and hearing through which they receive distorted information.

"A person with residual sight and hearing is often just as handicapped as a person who can neither see nor hear at all. What sound there is forms a curtain which in effect shuts one off from the immediate environment." (Nordstrom, 1984)

Some people, such as those with learning difficulties and some older people, experience further difficulties in processing the information they receive and making maximum use of their residual sight and hearing.
“Some elderly people with only slight impairments of sight and hearing often have a more difficult time making use of residual sight and hearing than young people with more severe impairments.” (Nordstrom, 1984)

Clearly, the circumstances of dual sensory impaired people are very varied, and it would be quite wrong to deny the range and diversity of their life experiences. The reality is that dual sensory impaired people are an extremely heterogeneous group.

The classification of dual sensory impairment

In an attempt to come to terms with this diversity, professionals in the field classify dual sensory impaired people into four distinct groups, based on the time of onset of their sensory impairments. This classification has resulted in expert-led attempts to identify their education and rehabilitation needs.

People deaf and blind from birth

Many of the people in this group are born 'dual sensory impaired as a result of maternal rubella or prematurity. They frequently have additional cognitive and physical impairments.

Congenitally deafblind children are recognised to have severe communication, developmental and educational problems. According to McInnes and Treffy (1982) they may:-

- “lack the ability to communicate with their environment in a meaningful way
- have a distorted perception of their world
- lack the ability to anticipate future events or the results of their actions
- be deprived of many of the most basic extrinsic motivations have medical problems which lead to serious developmental lags
- be mislabelled as retarded or emotionally disturbed
- be forced to develop unique learning styles to compensate for their multiple handicaps
- have extreme difficulty in establishing and maintaining interpersonal relationships.”

Much of the literature on deafblindness focuses on this group. Workers have stressed the importance of early diagnosis; skilled assessment and programme planning by professionals who have an understanding of dual sensory impairment; support for parents to assist them in the development of their child, including the provision of interveners who work on a one-to-one basis with the child to help them make sense of the world around them; specialist educational provision including post-sixteen further education and rehabilitation; employment opportunities or suitable day care; and supported living options, for example, "homes for life".
However, it is only recently that central government and local authorities in this country have begun to address some of these issues. Graham Hicks commented at the Second European Conference on Deafblindness in 1988:-

"The majority of low ability deafblind are those born with congenital rubella, many of whom were born in the early nineteen sixties. Unfortunately, the special educational and other needs of these people have never been fully recognised by the authorities, which has meant that in many cases suitable education placements have not been available. Many congenitally deafblind people have been and still are placed in mental institutions which are unsuitable. Even when a child has been lucky enough to receive special education and has acquired skills, there is often no suitable setting for them to move to afterwards, either for habitation, care or employment. The result has often been that the child or adult has either been placed in a mental institution or has returned to live with their parents. In cases where no educational or other placement has been found, parents have had to care for their deafblind child or adult for many years with little support."

**People deaf from birth who subsequently lose their sight**

A clear distinction has to be made between those people who are profoundly pre-lingually deaf, and those who have had at least some hearing for the early part of their life. The former are likely to use sign language as their first language for both expressive and receptive communication and the latter to have speech. The pre-lingually Deaf have their own community, culture and value systems, and it has been argued by some that they are not disabled, but are best seen as a minority group (e.g. Schein, 1986).

Ushers Syndrome is recognised to be the main cause of dual sensory impairment for both groups. It is a genetic disorder which is believed to affect between three and six percent of all children born deaf (Vernon, 1969) and to affect 3 in 100,000 of the general population (Hallgren, 1959; Kloepflor, Laguaita and McLaurin, 1966). It links hearing impairment with an eye condition called retinitis pigmentosa which causes a gradual deterioration of the retina, leading to a narrowing of the visual field (tunnel vision), and an inability to adjust to changes in illumination (night blindness).

Much attention has been focused on Type One Ushers Syndrome, which causes profound deafness, retinitis pigmentosa and vestibular dysfunction (balance problems). Type Two is linked to moderate or severe hearing impairment and retinitis pigmentosa. Recent research has found additional variations, such as milder and progressive hearing losses, and much variability on the progression of the eye condition.

The literature on Ushers Syndrome stresses the need for early diagnosis. However, screening of deaf and hearing impaired children using appropriate eye tests often does not take place, resulting in the children with the condition not being identified. They may be assumed to be clumsy or to be slow learners. It is recommended that people with Ushers Syndrome have access to counselling and rehabilitation services (including the teaching of new communication methods the provision of aids and mobility training) provided by professionals who fully understand the condition, who have the
necessary communication skills, and in the case of profoundly pre-lingually Deaf people, have an understanding of Deaf culture and language.

Some research has associated Ushers Syndrome with a high rate of psychiatric disorder, such as paranoia or schizophrenia (Hallgren, 1959; Hardison, 1977; Vernon 1969). It has been suggested that this illness is stress related.

Chronic stress may be induced by gradual loss of vision in persons who have learnt to cope with another major sensory disability, deafness, in part by relying more heavily on visual input. The most effective therapeutic interventions for this special group of people may well be supportive measures to assist in recognition of the stress related responses and in coping with the loss of vision and hearing, rather than the use of psychotropic medications other than to control acute symptoms." (Mangovich and Misiaszek, 1983)

People blind from birth who subsequently experience hearing loss

People who have had a visual impairment from birth are likely to have developed a dependence on hearing for both communication and orientation, although they will have speech and some may have learned to use Braille. With the onset of an additional hearing impairment, they can continue to use speech, but may need hearing aids and assistive listening devices. However, if the hearing impairment is severe, they may need to develop alternative communication methods such as the deafblind manual; previously learnt tactile methods, such as Braille may become even more crucial. They require access to counselling and rehabilitation services provided by professionals who understand dual sensory impairment.

People who acquire a hearing and visual impairment late in life

This is generally recognised to be the largest group, comprising mostly older people with speech, whose vision and hearing has deteriorated. However, only passing reference is made to this group, about whom little is known. The literature about sensory impairments among adults and older people is largely compartmentalised, dealing with each impairment separately.

"The presently available literature covers each sensori-perceptual loss of ageing separately and in no instance is information regarding multi-handicapped aged persons reported." (Wolanin and Philips, 1982).

The Helen Keller National Centre in America has recently begun to address the needs of this group. Martha Bagley has been appointed as a specialist for older people and has produced some awareness raising literature in which she states:-

"It is not uncommon for an older person to experience both a visual and hearing impairment. A combined sensory impairment such as this is often viewed as deafblindness. Deafblindness does not always mean a person is totally deaf or totally blind. Their impairment does, however, prevent them from seeing and hearing as well as
most other people. The combination of the two sensory impairments makes many everyday tasks difficult." (Bagley, 1989).

A small scale qualitative study entitled Beyond Refuge: Coping with Losses of Vision and Hearing in Later Life has been carried out by Luey et al. (1989). They carried out in-depth interviews with thirty older dual sensory impaired people and found that over fifty percent were receiving a minimal service for one sensory impairment, nothing was being done to address the special problems of the dual impairment, and basic services were not accessible to many people. Some agencies in Australia have also recently begun to address the needs of this group.

These categories of dual sensory impairment illustrate the very different communication needs of dual sensory impaired people. However, like all classification systems, they are an oversimplification; the danger is that collective assumptions are made on the basis of such a classification, assumptions which deny the unique experiences, needs and communication requirements of individuals.

**HOW MANY DUAL SENSORY IMPAIRED PEOPLE ARE THERE?**

Separate registers are maintained by local authorities of Deaf and hard of hearing people and blind and partially sighted people. Consultant ophthalmologists register visually impaired people as either blind or partially sighted, although as of April 1990 consultants have been asked to indicate if the individual has a "significant hearing impairment". Social Workers register hearing impaired people as deaf without speech, deaf with speech or hard of hearing. No registration system exists for those who are dual sensory impaired.

In recent years there has been increasing recognition that registers are unreliable and of limited use in the planning of services. For example:-

"It is generally accepted that the registers are not a reliable source of information on which to base service provision." (Department of Health, 1988a)

"In determining the numbers of people in their local area, it is not sufficient to allow for the numbers registered with local authorities; to assess the need for services, authorities will also need to consider the epidemiological information already available, as well as the information emerging from the OPCS Survey for Disabled People." (Department of Health, 1988b)

"Present definitions of "blind" and "partial sight" are but poor indications of who may be in need of help they give access to... there are many people in the community not presently eligible for registration who appear to have as many difficulties as those who are." (Culinan, 1977)
In reality, the numbers of dual sensory impaired people are unknown by service providers. Unfortunately, very little research has been done in this area, and has almost always been focused on single sensory impairment (for example Culinan(1977) and Davis(1989)).

**The prevalence of dual sensory impairment**

There are several different ways to estimate the size of a given population, such as dual sensory impaired people. These include epidemiological methods, clinical studies, and surveys using a questionnaire method. The results obtained depend on the method used, and vary widely according to the criteria of impairment and disability which are applied.

These factors make it extremely difficult to extrapolate the results of any published study to the local context. The difficulties are illustrated below for two populations of dual sensory impaired people those living in the community, and those living in residential care.

**Dual sensory impaired people in the community**

The Breaking Through report estimated a figure of 11,000 people for the United Kingdom and advised local authorities to assume a prevalence rate of 25 per 100,000. A national survey in Sweden (Nordstrom, 1984) recorded a figure of 18 per 100,000. Two local studies undertaken in Devon and Sunderland following the publication of the Breaking Through Report pointed to a prevalence rate of 40 per 100,000 (Holeman, 1990; Goodhall, 1990). On the basis of these studies, the numbers of dual sensory impaired people in Leicestershire would lie between 156 and 347.

However, other surveys would indicate much higher prevalence rates than this. For example, American estimates of the prevalence of deafblindness (Wolf et al, 1982) suggested that in the "non-institutionalised" population, the figures were as follows-

<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>NUMBERS</th>
<th>FREQUENCY PER 100,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>DEAFBLIND</td>
<td>41,859</td>
<td>20</td>
</tr>
<tr>
<td>DEAF AND SEVERELY VISUALLY IMPAIRED</td>
<td>25,481</td>
<td>12</td>
</tr>
<tr>
<td>BLIND AND SEVERELY HEARING IMPAIRED</td>
<td>357,818</td>
<td>169</td>
</tr>
<tr>
<td>SEVERELY VISUALLY AND HEARING IMPAIRED</td>
<td>309,117</td>
<td>146</td>
</tr>
<tr>
<td><strong>ALL CATEGORIES</strong></td>
<td><strong>734,275</strong></td>
<td><strong>346</strong></td>
</tr>
</tbody>
</table>

Table 1. Estimates of the prevalence of deafblindness in the community in the USA.

This study would suggest that the number of dual sensory impaired people in Leicestershire is 3003.
In this country, the OPCS Disability Survey (Martin, Meltzer and Elliot, 1988) findings for people who have a combined "seeing and hearing disability" suggests a figure of no less than 17,550 such people living in Leicestershire. The majority of these people, eighty-five percent, would have additional mental and/or physical impairments. The minority would therefore be expected to be solely dual sensory impaired.

The results obtained when a higher levels of functional difficulties are applied clearly illustrate the definition problem. Maureen Austen of the Social Policy and Research Unit of York University undertook some secondary analysis of the OPCS data, and estimated that there were 83,000 adults living in Britain who could not see well enough to recognise a friend across a room and could not use the telephone (Panel of Four, 1992). This represents a prevalence rate of about 150 per 100,000, yielding a figure of around 1300 for Leicestershire.

In a personal communication, she revealed that sixty-one per cent of these people had five or more additional disabilities; and only two per cent were solely dual sensory impaired. This further challenges the stereotypical view of dual sensory impairment, and points to a reality where most people are multiply impaired.

The RNIB Needs Survey found that only twenty-three percent of visually disabled people whose impairments were at registerable levels were actually registered as blind or partially sighted. They further estimated that thirty-five percent of visually impaired adults at registerable levels will have problems hearing someone speak in a normal voice in a quiet room (Bruce, et al., 1990). On the basis of their prevalence rates, there would be 4,175 registerable visually disabled people in Leicestershire who could be expected to have this degree of "hearing difficulties".

In summary, therefore, estimates of the population of dual sensory impaired people living in the community in Leicestershire based on previous surveys vary extremely widely, from 156 to 17,550. The reason for this vast disparity almost certainly lies in the problem of accurately defining dual sensory impairment (see below).

**Dual sensory impaired people in residential care**

Turning to those living in residential care, American research suggests that the prevalence rates for people living in residential establishments are far higher than for those living in the community (Wolf et al., 1982):
<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>NUMBERS</th>
<th>FREQUENCY PER 100,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>DEAFBLIND</td>
<td>3,451</td>
<td>130</td>
</tr>
<tr>
<td>DEAF AND SEVERELY VISUALLY IMPAIRED</td>
<td>442</td>
<td>25</td>
</tr>
<tr>
<td>BLIND AND SEVERELY HEARING IMPAIRED</td>
<td>1,548</td>
<td>89</td>
</tr>
<tr>
<td>SEVERE VISION AND HEARING IMPAIRMENTS</td>
<td>7,741</td>
<td>443</td>
</tr>
<tr>
<td>ALL CATEGORIES</td>
<td>13,182</td>
<td>754</td>
</tr>
</tbody>
</table>

Table 2. Estimates of the prevalence of deafblindness living in residential care in the USA

This study would suggest that the number of dual sensory impaired people living in residential establishments in Leicestershire is only fifty-two.

A more detailed examination of these data suggest that dual sensory impairment is not uniformly distributed throughout the population. Recent research has pointed to very high prevalence rates amongst older people, and people with learning difficulties. For example, the RNIB survey interviewers' direct observations indicated that forty-five percent of those aged over seventy-five years had difficulty hearing during the interviews. The authors of the survey concluded that:

"People and organisations who work with very old visually impaired people may assume that half are hard of hearing."

As the population is ageing, so too is the number of older dual sensory impaired people. Schein (1986) states:

"The people most affected by deafblindness are elderly persons. Recall that all deaf youths and all blind youths are half way to becoming deafblind. Put in other words, those who are deafened or blinded in early life can expect a decline in their unaffected sense as they grow older. Impairments of vision and audition are common after age sixty. About thirty-five percent of all persons sixty-five years of age and older have auditory impairment (Schein & Miller 1983). Past seventy-five years of age the rate of auditory impairment climbs to almost fifty percent. Similar rates apply to vision. Thus if a person is already deaf or blind the probability that person will become deafblind after sixty-five years of age is very high. Yet generally inadequate provision has been made to cater for the needs of elderly deafblind persons, either those who become deafblind early in life, or those who become deafblind in later life. The needs of those people must not be ignored, if for no other reason than that their numbers are increasing rapidly. By the year 2000, thirteen percent of the population will be aged sixty-five years of age or older. What seems to be poorly understood by social service planners is that a significant proportion
of the anticipated thirty-five million elderly people are very likely to be both visually and hearing impaired."

An examination of the OPCS Survey statistics for people with an intellectual impairment living in private households shows that eighteen percent have a combined "hearing and seeing disability". Diana Harries, in her report on services for people with learning difficulties and sensory impairment, concludes that one in three adults with learning difficulties are likely to have some form of sensory impairment, and that this figure is likely to increase to two in three by the year 2000 (Harries, 1991). The trend is for more children to survive with a "constellation" of severe impairments. It has been argued by some (see Snow, 1992) that because their needs and service requirements are so similar, the definition of congenital dual sensory impairment should be widened to include people who may have single sensory impairments and learning difficulties.

The traditional focus on clearly identifiable medical conditions, such as Usher's Syndrome has led to "deafblindness" being described as "a small incidence disability". For example, estimates of the number of people with Usher's Syndrome in Leicestershire lie between twenty-seven and fifty. The evidence above challenges this perspective, and account clearly has to be taken of the presence of dual sensory impairment amongst older people and people with intellectual impairments. The expected increase in older dual sensory impaired people, and of those people with learning difficulties has serious implications for planners of service provision in the years to come.

SERVICE PROVISION

Current service provision

Historically, the services provided by local authorities to meet the needs of disabled people have developed from a medical model which categorises disabled people in medical terms, for example blind people, deaf people, people with learning difficulties and so on. Staff have been trained and become experienced in working with these specific groups. This rigid service system has demonstrably failed to meet the needs of dual sensory impaired people. Words such as "unidentified", "forgotten" and "neglected" have been used to describe them.

"Altogether, deafblind people present a challenge to systems of management and the historically rigid patterns of service provision for deaf people and for blind people. "Ne'er the twain do meet" in many parts of the country, resulting in deafblind people falling through the net." (Department of Health, 1989)

Over-specialisation by staff in social services departments creates an inherent risk that people with multiple impairments will be pigeon-holed in order either to fit one professional specialism, or be allocated to the specialism which, in the workers view, relates to the primary disability." (Department of Health, 1993)

This pattern has tended to be repeated in the voluntary sector, with voluntary organisations nationally and locally campaigning on behalf of and providing services for single sensory disabled
people. Historically, dual sensory impaired people have been regarded by single sensory service providers as a small, distinct, marginal group; the prevalence studies quoted above show that this is clearly not the case.

Two national voluntary organisations have been established which campaign on behalf of dual sensory impaired people and provide some services. These are The National Deafblind League and Sense.

The National Deafblind League is a self-help group with many of its services being run by deafblind people. Its main aim is to "promote the social happiness of deafblind people and to interest the public on their behalf." It has established local clubs called "Rainbow Clubs" and a visiting service. The League produces a magazine and other information in Braille, Moon and large print for its members.

Sense, which was originally known as the National Deafblind and Rubella Handicapped Association, originally started as a parents' pressure group. It has since developed into a professional agency providing a variety of services mainly for children and adults who are congenitally dual sensory impaired. These services include a family advisory service, educational advisers and further education centres. Sense also works with people who have Ushers Syndrome, both directly in providing rehabilitation services, and indirectly in promoting awareness and understanding of the condition.

Two other national voluntary organisations which provide some services for dual sensory impaired people are the RNIB and the RNID. The RNID provides a residential unit and rehabilitation centre for deaf people with additional impairments, and currently employs two Project Workers on short term contracts to assist local authorities in the development of services for dual sensory impaired people. The RNIB has established a deafblind unit attached to one of its special schools. It provides a residential home with places for deafblind people, and also employs a Deafblind Services Consultant (Adults), whose role is to encourage and assist local authorities to develop services for deafblind people.

A new initiative

In recent years, there has been a growing recognition of the failure of service providers to meet dual sensory impaired people's needs. As a result, several initiatives have been undertaken. These include the coming together of interested parties and the commissioning of research and reports. At the same time, the passing of new legislation has attempted to address some of the defects of the present service system.

In 1986, all four voluntary organisations, the RNID, RNIB, Sense and the National Deafblind League, came together and formed the National Deafblind Services Liaison Group. A working party was established which produced a report called Breaking Through: Developing Services for Deafblind People (Deafblind Services Liaison Group, 1988). The aim of this report was to provide information to local authorities about dual sensory impaired people and their needs, and to encourage them to improve and develop services. A series of sixteen recommendations were made. This report led to several small scale studies being undertaken nationally, and to some local authorities like
Leicestershire establishing Forums of local statutory and voluntary agencies to address these recommendations.

In 1988, the Social Services Inspectorate of the Department of Health carried out an inspection of services for deafblind people in six local authorities. The result was the publication of the report Signposts Leading to Better Social Services for Deafblind People (Department of Health, 1989).

These two reports highlighted various issues in the provision of services to dual sensory impaired people, and suggested the actions that needed to be taken. These included:-

i) Identification. The need to raise awareness about dual sensory impairment amongst workers with deaf or blind people, learning disabled or older people; and to gather statistics on the population.

ii) Assessment. Assessments need to be carried out by staff who understand the effects of a dual impairment and who can communicate in the preferred method of the dual sensory impaired person. A multidisciplinary approach should be adopted. Local authorities need to develop skills and expertise in undertaking assessments of people with sensory impairments and learning difficulties.

iii) Communication. Staff working with dual sensory impaired people should receive additional training in communication techniques and methods. In the case of dual sensory impaired people with learning difficulties, Signposts stated:

"Social services and health care staff need to be alert to the special communication needs of those with sensory impairments to ensure their maximum potential is achieved through training and educational programmes.

iv) Day to Day Assistance/Access to Services. Guide Communicators should be provided to act as the "eyes and ears" of dual sensory impaired people.

v) Information. This should be provided in accessible formats.

vi) Management. One senior manager should have a designated role in ensuring that multidisciplinary advice help and assessments are carried out.

These two reports were to begin to put dual sensory impairment on the agenda. Other developments have since taken place.

In 1988, the Department of Education and Science issued a policy statement on "Educational Provision For Deafblind Children", and in 1990, Central Government funding was made available to allow some consortiums of local authorities to begin to develop educational provision for dual sensory impaired children. Leicestershire was a member of one of the consortiums to receive funding.
A one-year postgraduate teacher training course was also established at Birmingham University for teachers working with multi-sensory impaired children.

In 1989, the death occurred of Beverley Lewis, a twenty-three year-old woman who was born hearing and vision impaired, and with physical and learning disabilities. She had been living with her mother in a state of neglect and isolation, and questions were raised about the failure of her local authority to meet her needs and the circumstances surrounding her death. The Social Services Inspectorate of the Department of Health subsequently carried out inspections of services for people with multiple impairments in several Social Services Departments, including Leicestershire.

In 1991, Diana Harries published the results of a three-year research project on services for people with learning disabilities and sensory impairments, entitled "A Sense of Worth". This report found that lack of recognition of the needs of this group had resulted in non-existent or inadequate service provision. The sensory impairments of people with learning disabilities were often undiagnosed and untreated. Many people with a learning disability and sensory impairment were accommodated in long stay hospitals where their communication problems were not addressed, leading to severely challenging behaviour and lack of personal development. The report stated that:-

"Shortages of money and resources are realistic concerns. But while situations vary in detail, the single factor which stands out is that it is the attitudes of managers towards obtaining information and advice that distinguishes those districts and departments which have appropriate services from those which do not". (Harries, 1991).

In 1992, the Panel of Four (The British Association of the Hard of Hearing, the British Deaf Association, the National Deaf Children's Society and the Royal National Institute for the Deaf) set up a Commission to

"consider the full range of human aids to communication between all deaf and hearing people, and make recommendations for the improvement in the quality and quantity for both the short and the longer term."

The Commission considered the communication needs of deafblind people and concluded that:-

"What is needed above all is a recognition that deafblind people with their dual sensory disability are the most disadvantaged of the users in this report. It is not just the responsibility of the deafblind voluntary organisations to campaign on their behalf. WE ALL have a responsibility to campaign with, and on behalf of deafblind people." (Panel of Four, 1992).

The report recommended that:-

1. Deafblindness/dual sensory disability be recognised as a separate disability and not tucked away behind deafness or blindness.
2. Authorities recognise that the communication needs of deafblind people are unique to each individual.

3. Authorities recognise that all staff and carers need training in deafblind communication skills."

Recently, eight national disability organisations (Sense, Action for Blind People, Deaf Accord, Mencap, RADAR, RNIB, RNID, and The Spastics Society) have joined together to form Challenge, The Campaign for People With Multiple Disabilities.

In summary, the late Eighties saw a new collaboration between the national voluntary agencies in highlighting the needs of dual-sensory disabled people, and raised awareness by Central Government that these needs should be addressed. At the same time, major legislative changes have taken place which have attempted to rectify some of the historic failings of the service system.

Legislative changes

Recent legislative changes, such as the Disabled Persons Act and the Community Care legislation have placed an assessment of individual needs at the centre of service provision, and focused attention on the needs of carers.

For example, the NHS Community Care Act (1990) establishes a care management and assessment system which emphasises adapting

"services to needs rather than fitting people into existing services, and dealing with the needs of individuals as a whole rather than answering needs separately for different services." (Department of Health, 1991b).

Clearly, the definition of need which is adopted is crucial in this exercise. The Department of Health (1991b) guidance for practitioners defines need as

"the requirements of individuals to enable them to achieve, maintain or restore an acceptable level of social independence or quality of life, as defined by the particular care agency or authority."

Six broad categories of need are identified which should be covered in a comprehensive assessment:- personal/social care, health care, accommodation, finance, education/employment/leisure, and transport/access.

This definition of need is clearly professionally led, and is based on the notion that the need of disabled people is primarily to be restored or rehabilitated to some kind of "normality". Community care legislation is undoubtedly a major step forward, and has the potential to lead to improved service provision for dual sensory impaired people and their carers, if adequately resourced. However, in this report it will be argued that this legislation is based on a medical/individual model
of disability, which takes scant account of the environmental and social changes required by disabled people themselves.

The legislation, however, contains much well-considered arguments in favour of empowering service users and their carers. It targets many of the worst features of the old system and aims to produce a shift in influence away from services in favour of users and their carers. It creates a planning framework in which agencies must start to work much more closely together and places greater emphasis on consultation and collaboration at every level.” (The Audit Commission, 1992).

The overall aim of the Community Care Act is to enable people to live in their own homes wherever possible, with the provision of flexible services and support for carers a high priority. It aims to encourage "consumer choice", and to involve users and carers in the planning of services.

The local context - the situation in Leicestershire

In Leicestershire, several agencies provide the Social Work and Rehabilitation Services to sensory disabled people; the Health Authority, the Social Services Department, the Society for the Blind and the Centre for Deaf People. The Education Department employs a part-time specialist teacher and a part-time educational psychologist for dual sensory impaired children. They are currently employed on a temporary basis as part of a consortium of local authorities funded by Central Government.

Leicestershire has recently adopted "Living Options" as a model on which to base its service development. This is a framework for developing services for people with severe physical and sensory disabilities drawn up by the Prince of Wales Advisory Group on Disability, the Living Options Working Party and the Kings Fund Centre (Fielder and Twitchin, 1990). The model aims for the full integration of disabled people into society, and suggests that the basic components of an effective service system are:-

- A response point to users needs
- A place to live
- Personal support services
- Access to the community
- Specialist services
- Opportunities for personal development

The development of the Leicestershire project

In 1989, in response to the Breaking Through Report (Deafblind Services Liaison Group, 1988) the Leicestershire Society for the Blind decided to employ a Project Worker on a three year contract to identify dual sensory impaired people in the county, examine their needs and to make
recommendations for improved service provision. The Society was one of the first agencies in the country to take such positive action in response to this report.

A multi-agency support group was formed to assist the Project Worker comprising representation from the Society for the Blind, The Centre for Deaf People, the Social Services Department and The National Deafblind League. The group was later enlarged to include representatives from the Education Department and the Health Authority. The Society also agreed to the Project Worker enrolling for a higher degree with the Social Sciences Department of Loughborough University so that advice and support could be obtained with regard to the methodology of the research.

The project also benefited greatly from having the full support and backing of the Director of Social Services in Leicestershire. In January 1990, the Director of Social Services, Brian Waller, agreed to launch the project and chaired a conference on dual sensory impairment attended by one hundred and thirty professionals from various statutory and voluntary agencies in Leicestershire. The day had two main aims:-

a) To provide information and raise awareness about the needs and service requirements of dual sensory impaired people.

b) To introduce the local project and the "way forward" for Leicestershire. (A paper was presented by the Project Worker/Researcher)

The Director agreed to the setting up of a standing multi-agency forum (a sub-group of the Community Care Planning Group for Physical and Sensory Disabilities) specifically to address the issue of service provision for dual sensory impaired people. The planning group was to include the Project Worker and also to have dual sensory impaired and carer representatives.

The first task of this forum was to consider the recommendations of the Breaking Through Report for Leicestershire. A report was subsequently produced in October 1992 (Leicestershire County Council Community Care Planning Sub Group on Combined Hearing and Vision Disability, 1992). Currently the group is monitoring the progress of these recommendations and is developing a policy statement and code of practice in relation to services for dual sensory impaired people. The group will also be considering the findings of this research.

In addition to carrying out the research and participating in the planning group the Project Worker also undertook a range of other tasks; for example, some direct work with dual sensory impaired people, including assisting with a local social group, and providing advice and information to users, carers, and other professionals. A separate study was also undertaken into the needs of Asian dual sensory impaired people with a Project Worker employed by the Centre for Deaf People (Palmer and Kholi (1990)); and a study of the needs of carers. An international perspective was also gained with the award of the 1990 Dr Isabel Schwartz/Community Care Travel Fellowship. This enabled the Project Worker to participate in a one week training course at the Nordic Staff Training Centre in Denmark and to spend two weeks viewing services for dual sensory impaired people in both Denmark and Sweden.
There were clearly several advantages for the researcher in being employed by a local agency including ease of access to records, registers, and professionals, increased understanding of organisational practices, frequent and regular contact with the user group being studied and professionals in the field, and considerable administrative support. There was also the assistance of the steering group as outlined above and a planning group in existence to pursue the recommendations of the study. However the researcher was also mindful of the disadvantages of this situation including the influence of the agency's agenda on the research objectives; the possibility of bias; and the association of the researcher with a particular agency as opposed to having a neutral position. In reality the latter however were not felt to compromise the research.

RESEARCH AIMS AND APPROACH

The Aims of the Research

This study aimed to identify dual sensory impaired people living in Leicestershire, and to examine the needs of adult and older dual sensory impaired people in the light of existing theory, knowledge, policy and service provision.

There were three key objectives:-

1) To identify and describe the key characteristics of dual sensory impaired people living in Leicestershire.

2) To examine the needs of adults and older dual sensory impaired people.

3) To consider changes and improvements to current health and social care service provision.

The Approach Adopted in this Study

A number of issues needed to be considered when undertaking these objectives. These were concerned with the model of disability which underpinned the study, the approach to need which was to be adopted, the definition of the population which was accepted, and the methodology used.

Models of disability

Various models of disability have been proposed. The individual and medical models, implicitly accepted by health and social care agencies, have traditionally influenced policy and practice. People's "disability", their "problems" and experiences, are regarded as a direct result of their impairment; and the emphasis is on diagnosis, clinical intervention and categorisation. Assumptions are made about physical and mental "normality", and people's impairments are therefore the primary focus of attention.
The aim of the traditional approach is to rehabilitate people with impairments to be as "normal" as possible. Examples of this approach can be seen in the provision of hearing and low vision aids, and mobility and daily living skills training. Although many disabled people undoubtedly need and benefit from such specialist services which attempt to minimise the effects of their impairments, there can be ill effects:-

"If disabled people are also persuaded to idolise the normal then they in turn can fight a battle against feelings of low self-esteem, whilst being patronised by others who consider themselves 'normal'." (Department of Health, 1991a)

Individual and medical models of disability have been rejected by a growing number of disabled people and their organisations who have argued for the adoption of a social model of disability. In this view, disability is:

"the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have (physical) impairments, and thus excludes them from the mainstream of social activities". (UPIAS, 1976)

or

"the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to cultural, physical and/or social barriers." (DPI, 1981)

The social model of disability holds that the cause of disability lies totally within society and social organisation. Disability is a social state and not a medical condition; and disabled people as a group experience widespread discrimination, institutionalised throughout society. Under this model, professionals would work in partnership with disabled people and would aim to eliminate the social causes of disability.

Disabled people all over the world have begun to demand their rights, and in some countries such as Canada and the United States, legislation has been passed which seeks to remove the institutional barriers. Groups of disabled people in this country are currently demanding similar anti-discrimination legislation. Some disabled people experience additional disadvantage and discrimination on the basis of other factors, such as age, gender and race. Older people have also begun to demand their rights to full access to community activities. Age Concern have recently urged Local Authorities to develop a Charter of Rights to Community Care for Older People. They argue that the following equal opportunities statement should underpin all service delivery:-

"Each older person has the right to a life which maintains personal independence, safeguards privacy, offers genuine and informed choices, provides opportunities to enjoy and contribute to society as fully as possible and meets his/her social, cultural and individual needs." (Age Concern, 1989)
The medical establishment itself has recently begun to recognise that the medically-based model does not match disabled people's experience. In 1992, A Charter for Disabled People using Hospitals was produced by the Royal College of Physicians and the Prince of Wales Advisory Group. This stated:-

"Disabled people constantly encounter barriers due to negative attitudes and inaccessible environments. Some may experience added disadvantage because they are poor, old or members of black or ethnic minorities. Yet all have the right to equal participation and equal consideration in all the aspects of the society of which they are part, and equal treatment by all organisations established to meet their requirements."

Recent Department of Health reports such as Hear Me See Me (1991a) and Whose Life Is It Anyway (1993) have highlighted how the current medical model-based approach adopted by Social Services has failed to empower disabled people and facilitate their integration into society. The report Hear Me See Me concludes that more indirect work (i.e. working in a planned way "through" staff with other agencies and local communities) needs to take place, such as practice

"promoting recreational, social and educational opportunities for users and carers and challenging those attitudes and practices which impede a person's integration within the local community"

and advises

"setting up training schemes so that practitioners and managers can learn how our society has influenced attitudes towards disabled people, women and black and minority ethnic people."

The report Whose Life Is It Anyway recommends that local authorities should make explicit the model of disability that underpins their service delivery. This should encourage them to become more aware of the hidden assumptions which underlie much of current practice and service provision, and adopt a "needs led" approach informed by a social model of disability.

Before this can be achieved, however, it is also vital to have a clear understanding of the concept of need, and to be explicit about the assumptions which underpin it.

**Approaches to need**

Need is a crucial concept in the field of social policy. Harris (1987) states:-

"An individual is in need for the purposes of social policy to the extent that he lacks resources to participate as a full member of society in its way of life."

Bradshaw (1972) identified four different operational definitions of need:
a. Normative need. A desirable standard is laid down by an expert and if individuals or a group falls short of this standard, they are regarded as "in need". This way of thinking about need is seen where minimum standards of provision are set. Poverty, for example, has been defined by the European Council as half the national average wage. It can also be seen in the development and use of Disability Scales.

b. Felt need. Under this definition, need is equated with want. Traditionally, felt need has been the concern of Social Workers and Community Workers, who ask people whether they feel they need an item or service.

c. Expressed need. This is felt need turned into a demand. Examples include referral rates for Social Services, and waiting lists for operations.

d. Comparative need. This is measured by examining the characteristics of those who are in receipt of a service and then defining those who have similar characteristics but are not in receipt of a service as "in need". This can be seen in social surveys of the incidence of "pathologies", such as unemployment. The RNIB Needs Survey (Bruce, McKennell and Walker, 1991) measured both self-assessed and comparative need.

While these varying ways of thinking about and measuring need may seem different, they have generally been expert-led and service-led. Even felt needs have been implicitly equated with the services which are currently on offer.

Traditionally, need surveys in the field of disability, such as the Canterbury Survey of Handicapped People (Warren, 1974), which have been expert-led and service-led, have also been underpinned by the medical model of disability, which places the locus of change on the individual. In the past, need surveys have asked interviewees about their use and knowledge of the services which are available, and if they would like to receive them. The needs which are identified in this way are therefore inextricably bound up with current practice.

Similarly, professionals in the field are likely to suggest stock solutions based on their specialist training; these do not take into account the felt needs of the consumer, which may require wider societal changes if they are to be satisfied. Barnes (1991) argues

"Throughout the post-1945 period the expansion of the health and social support services for disabled people has been constructed upon the erroneous belief that disabled people are not competent to make decisions about their own individual service needs. This has far reaching negative implications for disabled people, since logic dictates that if they cannot assume responsibility for organising their own lives then they cannot assume the responsibilities of citizenship."

He argues that the rehabilitation services offered amount to a
"piecemeal welfare system of professionals and services specifically designed to help disabled people learn how to cope with impossible social, financial, housing and environmental difficulties which would be totally unacceptable to any other sections of the community".

This state of affairs is a consequence of both the model of disability adopted, and the concept of need which has been used when enquiring about the needs of disabled people. An alternative approach to the measurement of need may well have produced very different data upon which planners and service providers base their decisions.

A new theoretical approach to need has recently been developed by Doyal and Gough (1991) in which they argue that there are universal human needs. They identify two basic human needs - physical health and autonomy. According to their theory, specific groups such as those subject to racial oppression, women, and people with disabilities have the same basic human needs as other people, but are subject to "additional threats to their health and autonomy". As a result they "require additional and specific satisfiers and procedures to address and correct them". They argue that these groups will know their own requirements best and that they share a common experience of oppression.

Doyal and Gough state that human autonomy centres on the opportunity to engage in some form of socially meaningful activity. In their terms, to be denied the capacity for potentially successful participation in society is to be denied one's humanity. Their theory has informed this research, which has considered the satisfiers required by dual sensory impaired people to enable them to participate as full members of society.

The definition issue

The starting point of the research necessarily had to be the establishment of a clear definition of dual sensory impaired people. Experts in several countries have grappled over many years with the problem of defining dual sensory impaired people. Many definitions exist, perhaps one of the most well known being the "Nordic Definition" (Svingen, Friele and Jacobsen, 1987).

"A person is deafblind when she/he has a severe degree of combined visual and auditory impairment. Some deafblind people are totally deaf and blind, while others have residual hearing and residual vision. This means that the deafblind cannot automatically utilise services for the visually impaired or those with hearing impairments.

Thus, deafblindness entails extreme difficulties with regard to education, training, working life, social life, cultural activities and information. For those who are born deafblind or who acquire deafblindness at an early age, the situation is complicated by the fact that they often have additional problems of a personality or behaviour kind. Such complications further reduce their chance of exploiting any residual vision or hearing. Deafblindness must therefore be regarded as a separate disability which requires special methods of communication and coping with functions of every day life."
The Deafblind Services Liaison Group (1988) with their report Breaking Through adopted the following definition:-

"Persons are regarded as deafblind if they have a severe degree of combined visual and auditory impairment resulting in problems of communication, information and mobility."

There are at least three problems with this definition. First, it may be invalid; some people with severe impairments may not have these "problems", and yet others with more mild or moderate impairments, particularly in conjunction with impaired cognitive ability, may experience severe problems of communication, information and mobility. Burton (1990) in his study of deafblind people's needs found that this definition did not accurately describe the experience of a significant number of the people he interviewed. Second, it has questionable reliability; it requires the person who is deciding if a person meets the definition to have "expert" knowledge, for to have an understanding of the meaning "problems of mobility". It was this researcher's experience that professionals varied in how they understood and used the definition; some gave very careful consideration to an individual's functional abilities, whilst others just sought evidence of a dual sensory impairment Finally such a definition implies a clear causal link between dual sensory impairment and the functional problems, and takes no account of the environmental and social factors which cause their disability.

The reality is that people who have a significant vision and hearing impairment are a heterogeneous group of people who are extremely difficult to define. As Christine Johnson states in her report to the European Conference:-

"We should not talk of deafblind people and their "needs" in a collective way as this can lead to stereotyping and denying the range of diversity subsumed under that label."

(Johnson, 1988)

Nevertheless, in any research which attempts to identify dual sensory impaired people some form of definition is essential. Initially, in order to begin the process of identifying dual sensory impaired people, a broad functional description was adopted. This was based on a suggestion by Derek Burton (Burton, 1990). In this view dual sensory impaired people are people who:

"have a combined hearing and visual impairment resulting in communication difficulties and daily living problems."

The methodology used

A two stage approach was adopted in this research. The first stage comprised a quantitative survey to identify dual sensory impaired people living in Leicestershire, and to describe their key characteristics. It was not the intention to undertake a epidemiological survey, which would have been unrealistic given the resources available; accordingly, the approach was similar to that adopted
by two other local authorities (Sunderland and Devon) but the survey undertaken was more rigorous and extensive. Functional statements reflecting moderate-severe hearing and vision impairments were taken from the OPCS Disability Survey (1988) to act as a guide to the identification of individuals. Screening sheets containing these statements were then constructed and information obtained from a wide variety of sources including registers and records, professionals in statutory and voluntary agencies, and dual sensory impaired people themselves and their families. The results were then analysed using the SPSS computer package.

The second stage comprised a qualitative survey to examine the needs of adults and older dual sensory impaired people. It was decided to adopt an approach that would allow dual sensory impaired people to speak for themselves about their needs. The best method for achieving this is a qualitative study which aims to describe and understand the world as it is seen by the interviewees. A positive advantage of this approach is that it allows for depth and detail, and an increased understanding of the experience of the people studied. It also has the potential to suggest innovative service developments, grounded in the daily experience of disabled people.

This approach is also congruent with recent community care legislation, which has attempted to shift the emphasis away from a "service led" and "expert approach" to examining needs from a "consumer perspective". Unfortunately, the literature that is available about dual sensory impaired people has generally been written by "experts" in the field, and so there is very little information available about dual sensory impaired people's subjective experience. Wolf, in his review on research in deafblindness states:

"We know very little of the subjective experience of deafblind people. While communication issues may hinder both clients' abilities to express this information and researchers' abilities to receive it, information must nonetheless be made available. Not to have reliable data on aspects of deafblind clients' existential experience is to invite misunderstanding, misdiagnosis and mistreatment as a result of unquestioned assumptions and beliefs from the professional community." (Wolf, et al., 1982)

In-depth interviews were carried out with twenty four dual sensory impaired people. They were asked both about the difficulties and restrictions they experienced in their lives, and how they felt these could be made easier or be overcome; and about their satisfaction with services. It is recognised that a possible disadvantage of this approach is that as only a small number of people were interviewed, it may be difficult to generalise from the findings. However, about thirty percent of the adults who were identified were interviewed, although this was not the case for the older age group.

CONTRIBUTION TO CURRENT KNOWLEDGE

The quantitative survey undertaken to identify dual sensory impaired people and describe their key characteristics is the most extensive survey of its kind undertaken by a local authority in response to the Breaking Through report. It reveals some interesting and useful data on this group of under-researched people and challenges current thinking about the extent and nature of dual sensory
impairment. It also provides such useful lessons for future researchers considering undertaking a survey of this nature.

There has been very little research on the experience and needs of adults and older dual sensory impaired people and this study fills this gap in current knowledge. A fresh approach was also adopted by undertaking a qualitative study; experts in the disability field (Zarb, G., and Oliver, M. (1991)) have argued for more qualitative studies of disabled people's experience.

Service provision is currently geared towards either visually impaired or deaf people and little consideration is given to the needs of dual sensory impaired people. This study suggests changes and improvements to services which will inform statutory and voluntary service providers both locally and nationally.

THE ORGANISATION OF THE REPORT

The next chapter is concerned with the identification of dual sensory impaired people living in Leicestershire. Chapter 3 examines the needs of a sample of adults and older dual sensory impaired people, and discusses the implications for service providers. The final Chapter contains the conclusions and suggested actions which flow from the study. Additional information is contained within a series of Appendices.
CHAPTER TWO

THE IDENTIFICATION OF DUAL SENSORY IMPAIRED PEOPLE LIVING IN LEICESTERSHIRE
INTRODUCTION

The aim of the first stage of this research was to identify and describe the key characteristics of dual sensory impaired people living in Leicestershire. It was clearly impossible to undertake a rigorous epidemiological survey across the whole county of Leicestershire. One possibility might have been to carry out a survey in one part of the county and extrapolate the results to the whole county; however the researcher was restricted by the agency demands to see individuals identified county wide. Gordon (1986) reminds us that research is

"a question of balancing what is feasible in research resource terms with what is methodologically desirable"

It was decided therefore to adopt a similar approach to that recently taken by two other local authorities Sunderland, and Devon (Goodhall, 1990; Holeman, 1990) and carry out a survey using information obtained from a variety of different sources. However it was hoped that this study would be more extensive and thorough than previous work.

It was therefore decided to carry out this task in three ways. Firstly, by consulting existing registers; secondly, by asking professionals in a wide range of both statutory and voluntary agencies to identify dual sensory impaired people known to them; and thirdly by advertising the project to encourage "self identification". The results were then analysed and the implications for service providers considered.

METHODOLOGY

A considerable amount of time was spent considering the definition problem. The researcher consulted widely with experts in the field, including academics and researchers at the National Institute of Hearing and the RNIB research unit; professionals at the Nordic Staff Training Centre in Denmark; a national trainer from the Helen Keller Centre in New York; consultants at the local hospital; and other workers who had undertaken similar surveys. In addition, the available literature was examined, particularly epidemiological studies.

It was hypothesised that there was generally low awareness and understanding of the nature of dual sensory impairment and therefore a simple, easily understood, functional description was required to highlight the existence of the group and to raise awareness. Accordingly, dual sensory impaired people were introduced on a guidance leaflet as

"people who have a combined visual and hearing impairment resulting in communication difficulties and daily living problems"

The individuals who were so identified were then to be more accurately described on a questionnaire or screening sheet.

Developing a screening sheet
It was decided that in order to increase both validity and reliability, the screening sheet should use well tested questions from a reputable questionnaire, in this case the OPCS Disability Survey (1988). Functional statements were therefore taken from the "seeing" and "hearing" severity scales. (see Appendix I). Careful consideration was given to the particular level of functional problems chosen in consultation with other researchers in the field. Advice was given by Adrian Davis of the Institute of Hearing Research, in Nottingham, and Errol Walker, from the RNIB Research Unit as to the appropriate levels to indicate moderate and severe hearing and visual impairments. As registers and records were sometimes the only source of information available the functional statements also had to approximate to registration categories.

The other variables to be included on the screening sheet comprised the "key characteristics" which were identified through examining the literature, consulting with experts in the field and others who had undertaken surveys, and through discussions with the project steering group.

Advice with regard to the construction and administering of the questionnaire was sought from the literature on carrying out social surveys. (Moser and Kalton, 1971; de Vaus, 1990; and Stacey, 1969).

It was important that the screening sheet included all the key characteristics of a heterogeneous group of people and yet was simple, brief and user-friendly in order to encourage completion. It was recognised that some of the people completing the questionnaire would have limited knowledge of sensory impairment. The language used to describe the people being sought had to be carefully chosen to ensure that people with moderate vision and hearing impairments were also included. The words "poor vision" and "hearing difficulties" were therefore used deliberately. The questionnaire had to have an attractive layout and be set out in a way which enabled ease of inputting into the computer ready for analysis.

The Pilot

Several versions were constructed and tested on colleagues and once a version of the screening sheet had been constructed which appeared to be reasonably satisfactory, it was decided to carry out a pilot exercise in one particular district of the County.

Moser and Kalton (1971) identify several useful functions of a pilot but state the most valuable function to be testing out the adequacy of the questionnaire. J. Bell (1989) states:-

"All data gathering instruments should be piloted to test how long it takes respondents to complete them, to check that all questions and instructions are clear and to enable you to remove any items which do not yield useable data."

The pilot took place over a three month period. Unfortunately owing to the time involved in negotiating access to professionals in other agencies, only the Social Services Department, the
Society for the Blind and the Centre for Deaf People took part in the study. However, 130 screening sheets were completed and the pilot proved to be an extremely useful exercise.

Most of the professionals within Social Services who were likely to have contact with dual sensory impaired people were approached and asked to complete the screening sheets on people known to them. They were asked to evaluate the screening sheets by answering the following questions:

- How long did it take you to complete?
- Was the information/guidance leaflet easy to follow?
- Were any of the questions unclear? If so will you say which and why?
- Was the layout of the questionnaire clear/attractive?
- Any other comments?

On the basis of this exercise several major changes were made to the screening sheets including:

- Creating a third category for visual and hearing difficulties, called "Uncertain" to identify those who functioned as hearing or vision impaired, but whose impairments were difficult to diagnose or assess.
- Adding a further question "lives alone".
- Simplifying the question on "Time of Onset". (It was discovered that the answer to this question was frequently not known, but the question was considered too crucial to remove completely).
- Removing the question on additional disabilities which people experienced difficulty in answering.

It was also discovered that it was very important to stress that individuals were sought who had BOTH poor vision and hearing difficulties. Sheets were sometimes completed on single sensory impaired people. Some adjustments were also made to the guidance leaflet that accompanied the screening sheets.

In addition to important modifications to the screening sheets, improvements were also made to the systems for their dissemination and return; and an increased appreciation was gained of the roles of different professionals and of those likely to be most helpful in terms of identifying dual sensory impaired people.

A report of the findings of this initial small-scale study was presented to the Social Services Divisional Manager of this district. The final version of the screening sheet was as shown in Appendix 2.

Administration and dissemination of the screening sheet

Two versions of the questionnaire were constructed; one for professionals and one for dual sensory impaired people themselves. The details covered were identical, and included questions on age, gender, ethnicity, schooling, whether living alone or in residential care, presence of learning
difficulties, degree of vision and hearing difficulties, hearing aid usage, speech difficulties, method of communication, time of onset of impairments and registration category for later completion by the researcher. A guidance leaflet accompanying the screening sheets gave details about the project and the people who the project was trying to identify, and dealt with the issue of confidentiality (see Appendix 3). A leaflet relevant for each agency and a separate leaflet for dual sensory impaired people themselves were produced again covering the same basic details.

Both the guidance leaflet and screening sheets were printed on bright yellow paper, to have maximum impact, to ensure that they were not easily lost, and to maximise colour contrast for people with poor vision.

In order to heighten people's awareness, and make the screening sheet easy to return,

- two awareness raising fact sheets were written entitled "Identifying Vision and Hearing Impairments among Older People" and "People with Learning Disability and Sensory Impairments" (see Appendix 4), and
- a covering letter, personally signed, and a response form or reply slip to be returned (see Appendix 5)
- Prepaid addressed envelopes were enclosed, with a date allowing three weeks for the return of all screening sheets and the response form.

Between April 1991 and April 1992 screening sheets were disseminated widely across statutory and voluntary agencies in Leicestershire. A considerable amount of time was spent in negotiating with agencies to gain permission to carry out this part of the project. This generally involved writing to the Directors of organisations, giving full details about the project and reassurances about the issue of confidentiality. For the Leicestershire Health Authority, the research had to be approved by the Medical Ethics Committee.

Names and addresses of individuals were obtained. These personal details were needed both to avoid the problem of duplication, and for the second stage of the project, when a random sample of people were to be interviewed. It was agreed that when this stage was reached, no approach was to be made to potential interviewees without first contacting the agency that initially referred them, and a guarantee of confidentiality was given that personal details would not be entered onto the computer nor would anyone be allowed access to the screening sheets except for the researcher and clerical assistant.

It was important to maximise the effectiveness of the researcher's involvement with the professionals within each agency. Certain key professionals were likely to be able to help identify relatively large numbers of dual sensory impaired people, and these were generally approached on an individual face-to-face basis. Others, with less contact with dual sensory impaired people were also important, but with limited time available, were approached by attendance at team meetings or by telephone and/or letter. Additionally, many talks were given throughout this period in order to raise people's awareness about dual sensory impairment, and to encourage co-operation with the research and completion of the screening sheets.
Full details with regard to the administering of the screening sheets are outlined below:

**Social Services**

Professionals working in district offices

The Director of Social Services launched the project at a one day conference organised by the researcher and gave his full backing to the study. It was necessary to liaise initially with the Principal Assistants Disabled Persons in each division. (See Appendix 6) They sent a memo to all relevant managers about the study with a copy to the researcher. Contact was then generally made on an individual basis with Social Workers with Visually Impaired People; with some Social Workers with Older People; and the Social Workers with People with Learning Difficulties. Team meetings were attended of all Occupational Therapists, Home Care Organisers and some generic teams.

The approach adopted had to be pragmatic and flexible due to the different systems that operated across the divisions, and due to the major reorganisation that was taking place in the Department at the time. As much contact as possible was made prior to the restructuring of the Social Services Department and reminder letters were sent to all the newly formed teams in February 1992.

**County-wide services**

A team meeting of Managers of the Health Services Division was attended and they agreed to circulate the screening sheets and attached information to all Hospital Social Workers. Contact was also made with the Welfare Rights section, the Adult Placement Scheme and the Community Accommodation Project.

**Day centres and residential establishments**

A letter was prepared for all day centres and residential establishments in the county. This letter, along with the screening sheets, fact sheets etc., was then mailed to all registered establishments (County Council, Private and Voluntary) on the researchers behalf by the Registrations Department.

**Ethnic minority communities**

The Principal Officer for Race Relations was contacted and he advised on the appropriate actions to be taken with regard to targeting dual sensory impaired people from these groups.

All projects, day centres etc., for people from minority ethnic communities funded by the Social Services Dept were contacted by phone as well as by letter.

**Leicestershire Health Authority**
Initial contact was made with the Director of Public Health and the District Medical Officer. A report of the research was then submitted to the Medical Ethics Committee for approval. Once this had been granted an approach was made to all the Health Authority Units. In order to seek the cooperation of GPs, the General Manager of the Family Health Services Authority approached the local Medical Committee on behalf of the project, but they did not feel able to lend their support. The reasons given were:-

- It was too difficult for them to go through their records/lists to identify the relevant people.
- They had too many other requests.
- They felt the information in other available registers provided a good foundation.

A letter about the project was sent to all the Unit General Managers with a copy to the Director of Nursing Services. The Project Worker then discussed with the individual managers possible ways of identifying people. Some agreed to key staff being approached directly by the Project Worker, whilst others agreed to ensure their completion on the researcher's behalf. Some agreed to the display of posters in clinics. A particularly positive response was received from the Glenfield Unit who, in addition to devising ways of identifying dual sensory impaired people known to them, requested advice about environmental improvements to improve their facilities for sensory impaired people.

Contact was made with the Divisional Managers of the Community Unit and meetings attended of Occupational Therapists and Community Nurses throughout the county. The Inspector of Nursing Homes advised the researcher of the names and addresses of all registered nursing homes in the County, and agreed to assist the Project Worker in encouraging response. The Director of the Speech Therapy Service agreed to co-ordinate a response from the Speech Therapists of dual sensory impaired people known to them. A Senior Clinical Medical Officer from the Child Health Section identified children on behalf of the project by consulting the Child Health Register and local consultants.

The Hearing Services Manager agreed to disseminate the forms for a two month period amongst the technicians and hearing therapists; and access was given to a card index system which recorded details of those registered blind people seen by a hearing therapist.

A meeting took place with the Clinical Specialist of Profound Handicap and Sensory Difficulties at the local long stay hospital for people with learning disabilities, and he agreed to circulate the information and screening sheets to all wards and group homes and to co-ordinate the response.

Information was also obtained from the Mental Handicap Register. Over the preceding couple of years an intensive survey had taken place of all known people with learning disabilities in the county. Interviews had been carried out with the person's carer or nearest professional, using a very detailed 56 page questionnaire. At the time that the research was being carried out, 1324 people had been interviewed in the community, and 281 in hospitals. Still outstanding were 565 people in the community, including all the Asian people and 70 people living in long-stay hospitals.
The Centre for Deaf People

The Project Worker attended a staff meeting at the Centre for Deaf People and the screening sheets were handed out to all relevant members of staff, and returned on a monthly basis.

The Society for the Blind

A presentation was given to the staff at the Society for the Blind and screening sheets were distributed to Rehabilitation Workers, Development Workers and other relevant personnel. Systems were devised to ensure that screening sheets were completed on all newly registered people, new referrals and on individuals attending the Low Vision Aid Clinic.

Details about hearing impairment were also sought from registered blind and partially sighted people who had replied to an invitation to attend the Society’s Annual General Meeting. A total of 695 people responded to the invitation, and 104 of these people stated that they had difficulty hearing normal speech.

The Deaf with/without speech and Hard of Hearing registers and the Blind and Partial Sight registers.

The Blind and Partial Sight Registers were cross referenced with the Deaf with/without Speech and Hard of Hearing Registers. This was undertaken in the summer of 1991 with a repeat exercise being undertaken in March 1992, to check all those registered in the intervening months.

The Deaf and Hard of Hearing Registers did not contain details of people with a visual impairment. The Blind and Partial Sight Registers did include details of people who had an “additional hearing impairment”. This information was believed to have been recorded following a survey of all registered visually impaired people some years prior to the commencement of the project. Details of those people who were recognised by consultants completing the BD8 registration form to have a “significant hearing impairment” had also been entered onto the computer. Screening sheets were therefore completed on all those individuals identified as being hearing impaired on the Blind and Partial Sight Registers.

Unfortunately many of the questions on the form had to be marked as “Not Known” for those individuals where the only source of information was the register.

The Education Department

Contact was made with the Visual Impairment Peripatetic Service, and the Hearing Impairment Peripatetic Service, the Educational Psychology Service and the Community Education Unit.

A survey to identify dual sensory impaired children had recently been carried out by the Head of the Visual Impairment Service. Questionnaires had been sent to all relevant schools and units and this had resulted in the identification of 33 children. Access was given to this information.
The Employment Services

A letter was sent to the Regional Resettlement Adviser who advised that no dual sensory impaired people were known to the Disablement Resettlement Officers in Leicestershire, and that the register only recorded details of the "major impairment".

Voluntary Agencies

The large voluntary agencies in the County such as Age Concern, Mencap, WRVS and the Guild of the Disabled, were contacted, initially by letter and then by telephone to seek their co-operation with the project and to discuss the best method of arranging the distribution of the screening sheets. All smaller relevant voluntary organisations were contacted by letter and screening sheets, guidance leaflets and so on included.

Ethnic Minority Communities

Advice was sought from Asian professionals about how best to identify dual sensory impaired people in the ethnic minority communities. A list of organisations working with these communities was drawn up and a letter and screening sheets went to these agencies and groups requesting their co-operation with the project.

Advertising the Project

Two posters were created to inform the public about the project, and to encourage "self identification"; one was in English and the other in four Asian languages. (see Appendix 7) These posters were sent to a wide variety of agencies and groups with a request to display them including:

- Leicester City Council. Various departments co-operated including the Libraries, Recreation and Arts and Housing Department
- Local District Councils
- Family Health Services Authority who sent posters to all Health Centres and GP Practices.
- Eye Clinics
- The Hearing Services Centre
- The Resources Centre of the Society for the Blind
- The Centre for Deaf People
- All voluntary organisations and volunteer bureaux in the county.

The poster was published in the Leicester Link magazine which was delivered to all households in the city and the research was advertised on the "Disability Programme" of the local radio station. The Society for the Blind advertised it on two different information tapes, the County Sound magazine tape and their Information Tape.
The national voluntary organisation Sense agreed to assist with the project. Thirteen people were identified from their database.

Dealing with Non-Response and Processing the returned screening sheets

It was recognised that it was extremely important to obtain the highest response rate that was possible. Moser and Kalton (1971) point out that:-

"non-response is a problem because of the likelihood - repeatedly confirmed in practise
- that people who do not return questionnaires differ from those who do"

Following individual contacts, attendance at meetings or mail outs two reminders were given either by telephone or letter. (See Appendix8).

Systems were devised to check, and record all returned screening sheets. (see Appendix 9). Codes were entered onto the sheets for district of residence, agency and/or professional completing the form, registration details; and each individual was given a personal identification number. A method was designed to deal with multiple identification of the same individual. In this situation a new screening sheet was completed with a separate “multiple identification” number. In the small number of cases where there was discrepancy “the majority verdict” was taken.

A total of 2362 screen sheets were returned, but following checks, 69 people who had died were removed and 121 misidentified single sensory impaired people. Of the remaining 2172 sheets 710 were multiplicates, leaving a total of 1462 people successfully identified.

All data from the screening sheets were then entered into a computer by staff at the Computer Centre of Loughborough University. The resulting data was analysed by using SPSS (The Statistical Package for Social Scientists).

THE FINDINGS

The following is a summary of the findings revealed by the analyses. The most significant have been drawn out. Further detailed statistics by age group are presented in Appendix 10 but are not commented upon in the main body of the text.

Overall numbers of dual sensory impaired people

The population of Leicestershire is 867,521. The total number of dual sensory impaired people identified was 1462. This is equivalent to 169 people per 100,000. This is markedly higher than other recent studies have found which have used similar criteria and methods. The results were then further broken down by considering a number of variables. These were:- age; ethnicity; gender; severity of vision/hearing difficulties; time of onset of vision/hearing difficulties; method of
communication; learning difficulties; type of accommodation; registration; and district of residence. These more detailed results are presented below.

**Age**

<table>
<thead>
<tr>
<th>AGE GROUPS</th>
<th>NUMBER</th>
<th>% OF TOTAL POPULATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 19</td>
<td>61</td>
<td>4.2</td>
</tr>
<tr>
<td>20 - 64</td>
<td>160</td>
<td>11.5</td>
</tr>
<tr>
<td>65 - 74</td>
<td>91</td>
<td>6.2</td>
</tr>
<tr>
<td>75 - 84</td>
<td>369</td>
<td>25.3</td>
</tr>
<tr>
<td>85+</td>
<td>781</td>
<td>53.4</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1462</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 3. The number of dual sensory impaired people identified, and as a proportion of the total population, by age.

The data show a marked skew towards older people. Over 78% of the population was over the age of seventy-five years. The average age was seventy-eight years.

**Ethnicity**

The total number of people from minority ethnic communities in Leicestershire is 87,481. This figure represents 10% of the total population of Leicestershire. In Leicester city, 27% of people are from minority ethnic communities; the majority of these are Asian.

<table>
<thead>
<tr>
<th>ETHNIC GROUP</th>
<th>NUMBER</th>
<th>% OF TOTAL POPULATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>WHITE</td>
<td>1414</td>
<td>96.7</td>
</tr>
<tr>
<td>ASIAN</td>
<td>38</td>
<td>2.6</td>
</tr>
<tr>
<td>BLACK CARIBBEAN</td>
<td>3</td>
<td>0.2</td>
</tr>
<tr>
<td>BLACK OTHER</td>
<td>1</td>
<td>0.1</td>
</tr>
<tr>
<td>CHINESE</td>
<td>1</td>
<td>0.1</td>
</tr>
<tr>
<td>POLISH</td>
<td>1</td>
<td>0.1</td>
</tr>
<tr>
<td>NOT REPORTED</td>
<td>4</td>
<td>0.3</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1462</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 4. The number of dual sensory impaired people identified, and as a proportion of the total population, by ethnic origin.

The total number of people identified by this study from minority ethnic communities was forty-four (3.1% of the population identified). This represents a figure of 50 people per 100,000. Of these, almost all were Asian.
Within the Asian dual sensory impaired population, there were more males than females (72% vs. 28%); only one Asian person lived alone, while five Asian people lived in residential care; and four individuals used signs to communicate.

The following comparisons were made between the Asian community and the remaining dual sensory impaired people identified:

1. Age

More Asian people were identified aged under sixty-five years (42% vs. 14%).

2. Combined vision and hearing difficulties

A higher percentage of Asian people had a severe hearing impairment combined with a severe visual impairment (29% vs. 15%); a higher proportion were congenitally dual sensory impaired (18% vs. 3%).

3. Learning difficulties

More Asian people were described as having learning difficulties (32% vs. 11%).

4. Communication

Fewer Asian people wore a hearing aid (24% vs. 41%). More Asian people had speech difficulties (29% vs. 11%).

5. Registration

There were some differences in the percentages of Asian people who were registered as having visual difficulties as compared to other dual sensory impaired people. For example, there were more Asian people registered blind (58% vs. 47%), but fewer registered as partially sighted (13% vs. 22%).

Registration figures for hearing impairment were similar to the average for other dual sensory impaired people.
Gender

<table>
<thead>
<tr>
<th>GENDER</th>
<th>NUMBER</th>
<th>% OF TOTAL POPULATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>FEMALE</td>
<td>984</td>
<td>67.3</td>
</tr>
<tr>
<td>MALE</td>
<td>474</td>
<td>32.4</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>4</td>
<td>0.3</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1462</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 5. The number of dual sensory impaired people identified, and as a proportion of the total population, by gender.

About two thirds of the total population was female and one third was male.

1. Gender by age

As age increased so did the percentage of females; under nineteen years, there were 44% females vs. 56% males; between twenty and sixty-four years, there were 55% females vs. 45% males; and above the age of sixty-five years, the ratio of females to males rose to 71% vs. 28%.

2. Gender by time of onset

A higher percentage of males than females were born with visual difficulties (11% vs. 5%) and with hearing difficulties (7% vs. 5%).

3. Gender by speech difficulties

More males than females had speech difficulties (18% vs. 5%).

4. Gender by learning difficulties

More males with learning difficulties were identified than females (58% vs. 42%).

5. Gender by accommodation

Nearly 22% of the population lived alone; nearly 37% lived in residential care; the nature of the accommodation of the remaining proportion was not examined, but it may be assumed that most are living with others such as family or friends in the community.

However, the analysis shows that a high percentage of the people who lived alone were female. (80% female vs. 20% male). Similarly, over three-quarters of the population who lived in residential care were also women. (77% female vs. 23% male).
This table shows the numbers and percentages of the various combinations of hearing and vision difficulties.

<table>
<thead>
<tr>
<th>Severe Visual</th>
<th>Moderate Hearing</th>
<th>Uncertain Hearing</th>
<th>Not Known</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>SEVERE</td>
<td>MODERATE</td>
<td>UNCERTAIN</td>
<td>NOT</td>
<td>TOTAL</td>
</tr>
<tr>
<td>HEARING</td>
<td>HEARING</td>
<td>HEARING</td>
<td>KNOWN</td>
<td></td>
</tr>
<tr>
<td>SEVERE</td>
<td>MODERATE</td>
<td>UNCERTAIN</td>
<td>NOT</td>
<td>TOTAL</td>
</tr>
<tr>
<td>VISUAL</td>
<td>VISUAL</td>
<td>VISUAL</td>
<td>KNOWN</td>
<td></td>
</tr>
<tr>
<td>MODERATE</td>
<td>MODERATE</td>
<td>MODERATE</td>
<td>MODERATE</td>
<td></td>
</tr>
<tr>
<td>UNCERTAIN</td>
<td>UNCERTAIN</td>
<td>UNCERTAIN</td>
<td>UNCERTAIN</td>
<td></td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>NOT KNOWN</td>
<td>NOT KNOWN</td>
<td>NOT KNOWN</td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>TOTAL</td>
<td>TOTAL</td>
<td>TOTAL</td>
<td></td>
</tr>
</tbody>
</table>

Table 6. The number of dual sensory impaired people identified, and as a proportion of the total population, by severity of both hearing and vision difficulties.

The data on two groups of people are further analysed below.

1. People with severe/severe combined vision and hearing difficulties

Only fifteen percent of the total population were in this group. The majority (81%) were aged seventy-five years and over. Fifteen percent were described as having learning difficulties.

2. People with "uncertain" vision and hearing difficulties

The data on "uncertain" hearing and vision difficulties reveal some interesting trends.

i. Residential care

Sixty-five percent of people with uncertain hearing difficulties and eighty-two percent of people with uncertain visual difficulties lived in residential care.

ii. Learning difficulties

Fifty-five percent of people with uncertain hearing difficulties and thirty-three percent of people with uncertain visual difficulties had learning difficulties.

iii. Speech difficulties
Forty-five percent of people with uncertain hearing difficulties and thirty-six percent of people with uncertain visual difficulties had speech difficulties.

These data have implications for the screening of residential populations and people with learning disabilities.

### Time of onset of visual and hearing difficulties

<table>
<thead>
<tr>
<th></th>
<th>CONGENITAL VISUAL</th>
<th>ADVENTITIOUS VISUAL</th>
<th>NOT KNOWN</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>CONGENITAL HEARING</td>
<td>61 (4.2%)</td>
<td>21 (1.4%)</td>
<td>20 (1.4%)</td>
<td>102 (7.0%)</td>
</tr>
<tr>
<td>ADVENTITIOUS HEARING</td>
<td>10 (0.7%)</td>
<td>718 (49.0%)</td>
<td>33 (2.3%)</td>
<td>761 (52.0%)</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>9 (1.0%)</td>
<td>39 (2.8%)</td>
<td>549 (37.6%)</td>
<td>597 (41.0%)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>80 (5.5%)</td>
<td>778 (53.2%)</td>
<td>602 (41.2%)</td>
<td>1460 (100%)</td>
</tr>
</tbody>
</table>

Table 7. The number of dual sensory impaired people identified, and as a proportion of the total population, by time of onset of both hearing and vision difficulties.

Although there was a very high number of "Not Known" responses to this question (41% of cases), the clearest finding was that most dual sensory impaired people were adventitiously impaired. The vast majority (96%) of those who had developed a hearing and vision impairment later in life were aged sixty-five years and over; and seventy-two percent were female.

In contrast, seventy percent of those who were born with both hearing and visual difficulties were under the age of twenty-five years; for thirty-eight percent of this group, both sensory impairments were severe. Seventy percent of this group had learning difficulties; and sixty-two percent had speech difficulties.

### Method of communication

Several topics were probed in this important area; the wearing of hearing aids, the use of signs or sign language, and the presence of speech difficulties.
1. Hearing aid usage

<table>
<thead>
<tr>
<th>HEARING AID USER</th>
<th>NUMBER</th>
<th>% OF TOTAL POPULATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>593</td>
<td>40.6</td>
</tr>
<tr>
<td>NO</td>
<td>455</td>
<td>31.1</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>414</td>
<td>28.4</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1462</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 8. The number of dual sensory impaired people identified, and as a proportion of the total population, by hearing aid usage.

Forty percent of the population wore a hearing aid. Fifty-nine percent of people who lived alone wore an aid, whilst forty percent of those in residential care wore an aid. Of those people with learning difficulties, only twenty-one percent wore an aid.

Only one third of hearing aid users were registered as hard of hearing.

2. Use of signs or sign language

<table>
<thead>
<tr>
<th>USES SIGNS</th>
<th>NUMBER</th>
<th>% OF TOTAL POPULATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>48</td>
<td>3.3</td>
</tr>
<tr>
<td>NO</td>
<td>1087</td>
<td>74.4</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>327</td>
<td>22.4</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1462</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 9. The number of dual sensory impaired people identified, and as a proportion of the total population, by use of signs or sign language.

The use of signs or sign language was extremely low (3.3%). Seventy-one percent of those using signs or sign language had speech difficulties. Fifty-eight percent had learning difficulties; and fifty percent lived in residential care.
Manual methods used

The methods used to communicate manually were identified in only thirty-five cases.

<table>
<thead>
<tr>
<th>METHOD</th>
<th>NUMBER</th>
<th>% OF TOTAL POPULATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>DEAFBLIND MANUAL</td>
<td>7</td>
<td>0.5</td>
</tr>
<tr>
<td>DEAFBLIND</td>
<td>1</td>
<td>0.1</td>
</tr>
<tr>
<td>MANUAL/GESTURES</td>
<td>3</td>
<td>0.2</td>
</tr>
<tr>
<td>BSL/GESTURES</td>
<td>3</td>
<td>0.2</td>
</tr>
<tr>
<td>BSL/GESTURES/DB MANUAL</td>
<td>1</td>
<td>0.1</td>
</tr>
<tr>
<td>MAKATON</td>
<td>4</td>
<td>0.3</td>
</tr>
<tr>
<td>MAKATON/GESTURES</td>
<td>2</td>
<td>0.1</td>
</tr>
<tr>
<td>GESTURES</td>
<td>14</td>
<td>1.0</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>35</strong></td>
<td><strong>2.5</strong></td>
</tr>
</tbody>
</table>

Table 10. The number of dual sensory impaired people identified, and as a proportion of the total population, by manual methods used.

The stereotypical deafblind person is regarded as a deafblind manual or BSL user. In fact, these methods were very uncommon. In addition, there were only three deafblind manual users under the age of sixty-five; and only one used this as his sole method of communication. Six of this group of deafblind manual users were over sixty-five years old; their average age was seventy-nine. Similarly, several of the British Sign Language users were familiar with some signs but not fluent in the language.

3. Presence of speech difficulties

<table>
<thead>
<tr>
<th>HAS DIFFICULTIES</th>
<th>NUMBER</th>
<th>% OF TOTAL POPULATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>165</td>
<td>11.3</td>
</tr>
<tr>
<td>NO</td>
<td>992</td>
<td>67.9</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>305</td>
<td>20.9</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>1462</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Table 11. The number of dual sensory impaired people identified, and as a proportion of the total population, by presence of speech difficulties.

Two-thirds of the population under the age of twenty had speech difficulties; fifty percent of those aged between twenty and sixty-four years had speech difficulties; but this applied to only four percent of those over sixty-five years.
Fifty percent of dual sensory impaired people with speech difficulties lived in residential care, and seventy percent also had learning difficulties.

Twenty-one percent of people with speech difficulties communicated by sign language or by using signs.

Many more people with speech difficulties were described as having "uncertain" hearing difficulties than were other dual sensory impaired people (30% vs. 4.5%); and more people with speech difficulties were described as having "uncertain" visual difficulties (15% vs. 3.2%).

**Learning difficulties**

<table>
<thead>
<tr>
<th>HAS DIFFICULTIES</th>
<th>NUMBER</th>
<th>% OF TOTAL POPULATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>174</td>
<td>11.9</td>
</tr>
<tr>
<td>NO</td>
<td>1250</td>
<td>85.5</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>38</td>
<td>2.6</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1462</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 12. The number of dual sensory impaired people identified, and as a proportion of the total population, by learning difficulties.

Nearly twelve percent of the total population had learning difficulties. However, almost all of them were under the age of sixty-five. Fifty-three children and young people aged under twenty years and one hundred and six adults were identified. These figures represent eighty-two percent of the children and young people under twenty with a dual sensory impairment, and sixty-six percent of the adults aged between twenty and sixty-four years. There were more males than females (59% vs. 41%).

Sixty-five percent of people with learning difficulties lived in residential establishments, far higher than the proportion of all other dual sensory impaired people (32.8%). Two people attended a Further Education Unit for Deaf/Blind people; one person attended a Further Education College.

A much lower percentage wore hearing aids than other dual sensory impaired people (17% vs. 44%) and a much higher percentage had speech difficulties (64% vs. 4%) and communicated by signing (17% vs. 1.4%).

The time of onset was not known for seventy percent of the population with learning difficulties. More people with learning difficulties were described as having "uncertain" visual difficulties than others (13% vs. 7%). For hearing difficulties, the figures were even more disparate (31% vs. 1%).

There were fewer people with learning difficulties registered as blind in comparison with others (41% vs. 49%); and many fewer registered as partially sighted (6% vs. 24%).
There were four people with learning difficulties registered as deaf with speech and four as deaf without speech. The percentage of learning disabled people registered as hard of hearing was much smaller than for other dual sensory impaired people (4% vs. 28%).

**Type of accommodation**

Two questions were asked - did people live in residential care or live alone?

1. Residential care

First, the number of dual sensory impaired people as a percentage of the total number of people in residential care in Leicestershire was examined.

<table>
<thead>
<tr>
<th>AGE</th>
<th>NUMBERS</th>
<th>% OF TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 64</td>
<td>75</td>
<td>5.0</td>
</tr>
<tr>
<td>65+</td>
<td>461</td>
<td>8.4</td>
</tr>
<tr>
<td>TOTAL</td>
<td>536</td>
<td>7.7</td>
</tr>
</tbody>
</table>

Table 13. The number of dual sensory impaired people in residential care, and as a proportion of the total population in residential care in Leicestershire, by age.

This overall figure of 7.7% is over ten times higher than that identified by Wolf (1982). In addition, this table disguises the fact that seventy-eight percent of the older dual sensory impaired people in residential care were over the age of eighty-five years; they represent 13.8% of the total residential care population over this age.

i. The proportion of people living in residential care who were dual sensory impaired

<table>
<thead>
<tr>
<th>RESIDENTIAL</th>
<th>NUMBER</th>
<th>% OF TOTAL POPULATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>536</td>
<td>36.7</td>
</tr>
<tr>
<td>NO</td>
<td>875</td>
<td>59.8</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>51</td>
<td>3.5</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1462</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 14. The number of dual sensory impaired people identified, and as a proportion of the total population, by residential care.

Nearly thirty-seven percent of the population lived in residential care. The majority of people (77%) were female.
ii. The age of dual sensory impaired people living in residential care

<table>
<thead>
<tr>
<th>AGE</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 19</td>
<td>4</td>
<td>0.7</td>
</tr>
<tr>
<td>20 - 64</td>
<td>71</td>
<td>13.2</td>
</tr>
<tr>
<td>65 - 74</td>
<td>18</td>
<td>3.4</td>
</tr>
<tr>
<td>75 - 84</td>
<td>85</td>
<td>15.9</td>
</tr>
<tr>
<td>85+</td>
<td>358</td>
<td>66.8</td>
</tr>
<tr>
<td>TOTAL</td>
<td>536</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 15. The number and proportion of dual sensory impaired people living in residential care by age.

The majority (86%) of those living in residential care were over the age of sixty-five years.

iii. The presence of learning difficulties in dual sensory impaired people living in residential care

Overall, fifteen percent of those identified in the residential care group had learning difficulties; however, sixty-five of the seventy-one people (81%) aged between twenty and sixty-four years who were living in residential care had learning difficulties.

iv. Communication methods used by dual sensory impaired people living in residential care

A higher percentage communicated by signing as compared to other dual sensory impaired people population (4.5% vs. 2.6%). Fifty percent of the total population identified as using signs or sign language lived in residential care. Five methods were identified.

<table>
<thead>
<tr>
<th>METHOD</th>
<th>NUMBER</th>
</tr>
</thead>
<tbody>
<tr>
<td>DEAFBLIND MANAUAL</td>
<td>4</td>
</tr>
<tr>
<td>GESTURES</td>
<td>6</td>
</tr>
<tr>
<td>MAKATON</td>
<td>3</td>
</tr>
<tr>
<td>MAKATON/GESTURES</td>
<td>3</td>
</tr>
<tr>
<td>BSL/GESTURES</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 16. The number of people living in residential care using different manual communication methods

v. The registration of dual sensory impaired people living in residential care

A smaller percentage of people living in residential care were registered as blind compared to other dual sensory impaired people (37% vs. 54%); and similarly a smaller percentage were registered as partially sighted (12% vs. 28%).
There was a slightly smaller difference in respect of registration for hearing difficulties (20% vs. 30%).

2. Living alone

i. The proportion of dual sensory impaired people living alone

<table>
<thead>
<tr>
<th>LIVES ALONE</th>
<th>NUMBER</th>
<th>% OF TOTAL POPULATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>318</td>
<td>21.8</td>
</tr>
<tr>
<td>NO</td>
<td>841</td>
<td>57.5</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>303</td>
<td>20.7</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1462</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 17. The number of dual sensory impaired people identified, and as a proportion of the total population, by whether they lived alone.

Nearly twenty-two percent of dual sensory impaired people lived alone. Of this group, the majority (80%) were female.

ii. The age of dual sensory impaired people living alone

Ninety-three percent of the people who were living alone were aged over 75 years. (58% of these people were aged 85+).

Registration

<table>
<thead>
<tr>
<th></th>
<th>DEAF W/O SPEECH</th>
<th>DEAF WITH SPEECH</th>
<th>HARD OF HEARING</th>
<th>NOT REGISTERED</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>BLIND</td>
<td>5</td>
<td>7</td>
<td>202</td>
<td>438</td>
<td>697 (47.4%)</td>
</tr>
<tr>
<td>PARTIALLY SIGHTED</td>
<td>2</td>
<td>7</td>
<td>87</td>
<td>220</td>
<td>316 (21.6%)</td>
</tr>
<tr>
<td>NOT REGISTERED</td>
<td>4</td>
<td>2</td>
<td>70</td>
<td>373</td>
<td>449 (30.7%)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>11</td>
<td>16</td>
<td>359</td>
<td>1076</td>
<td>1462 (100%)</td>
</tr>
</tbody>
</table>

Table 18. The number of dual sensory impaired people identified, and as a proportion of the total population, by registration.

About one third (30.7%) of those identified were not registered as visually impaired, and approximately three-quarters (73.6%) were not registered as hearing impaired.
Only twelve people (0.8%) were registered as blind and deaf with/without speech.

**District of residence**

<table>
<thead>
<tr>
<th>AREA</th>
<th>NUMBER</th>
<th>% OF TOTAL</th>
<th>NUMBER PER 100,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>NORTHWEST LEICS</td>
<td>132</td>
<td>9.0</td>
<td>164</td>
</tr>
<tr>
<td>CHARNWOOD</td>
<td>197</td>
<td>13.5</td>
<td>139</td>
</tr>
<tr>
<td>MELTON MOWBRAY</td>
<td>76</td>
<td>5.2</td>
<td>168</td>
</tr>
<tr>
<td>RUTLAND</td>
<td>26</td>
<td>1.8</td>
<td>82</td>
</tr>
<tr>
<td>MARKET HARBOROUGH</td>
<td>102</td>
<td>7.0</td>
<td>150</td>
</tr>
<tr>
<td>HINCKLEY/ BOSWORTH</td>
<td>190</td>
<td>13.0</td>
<td>197</td>
</tr>
<tr>
<td>BLABY</td>
<td>106</td>
<td>7.3</td>
<td>128</td>
</tr>
<tr>
<td>OADBY/ WIGSTON</td>
<td>87</td>
<td>6.0</td>
<td>168</td>
</tr>
<tr>
<td>LEICS. CITY WEST</td>
<td>254</td>
<td>17.4</td>
<td>196</td>
</tr>
<tr>
<td>LEICS. CITY EAST</td>
<td>276</td>
<td>18.9</td>
<td>196</td>
</tr>
<tr>
<td>OUT OF COUNTY</td>
<td>3</td>
<td>0.2</td>
<td>-</td>
</tr>
<tr>
<td>NOT REPORTED</td>
<td>13</td>
<td>0.9</td>
<td>-</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1462</td>
<td>100</td>
<td>169</td>
</tr>
</tbody>
</table>

Table 19. The number of dual sensory impaired people identified, and as a proportion of the total population, by district of residence.

The numbers identified in each district range from 82 to 197 per 100,000.

**DISCUSSION**

The total number of people identified in this study was 1462. This figure is equivalent to 169 people per 100,000, over four times higher than the figure of 40 per 100,000 which previous local studies (undertaken using similar methods) have found. This may be because great care was taken to undertake a comprehensive survey of all service providers, and to advertise the project widely in the community. As a result, the data are very instructive about the characteristics of the dual sensory impaired population known to professionals working in this area.

The survey also had the very positive effect of increasing the awareness and understanding of dual sensory impairment locally, and, it is to be hoped, improved the ability of professionals to recognise and identify dual sensory impaired people.

**A typical respondent**
A high proportion of the population were adventitiously impaired females over the age of seventy-five years, living in the community, who relied on their residual hearing and sight for communication. This picture is very different from the stereotypical profoundly deaf/totally blind person using the deaf/blind manual for communication, and may reflect the changes in the epidemiology of dual sensory impairment over recent years.

This picture confirms one of the comments made at a seminar on the Breaking Through report (Deafblind Services Liaison Group, 1988).

"One of the problems in helping deafblind people is that the perspective tends to be confined to a very narrow image of people who are profoundly deaf or totally blind and can communicate, if at all, by manual methods yet the largest group are elderly people whose hearing and sight have deteriorated substantially in later life, and for whom tactile communication is foreign".

Scant attention has been paid to this group of older dual sensory impaired people in the past. This is a growing population, and they are experiencing dual sensory impairment at a time when the personal resources of many are dwindling; when they may be experiencing other illnesses and impairments; and when they are almost certainly being disadvantaged by society's ageist practices and attitudes. Clearly, the implications for the planning and provision of current and future services are profound.

Sub groups

The significance of some of the findings are described below under a number of headings - gender, children, the population in residential care, people with learning difficulties, minority ethnic communities and people on registers.

Gender

Overall, there was an age-related gender bias; females in the total population outnumbered males 2:1, which was almost certainly due to the tendency of females to live longer than males. On the other hand, more males than females were identified under the age of nineteen years and amongst those people with learning difficulties.

Children

Despite being advised early on in the project that children would be relatively easy to identify, this was not found to be the case. It was clearly difficult to assess those children who had "severe developmental delay". This led to disagreements amongst professionals about whether certain children should be described as being dual sensory impaired. Details obtained from different sources reflected this lack of consensus. A significant number were placed in the "uncertain" categories, particularly for hearing difficulties.
As would be expected, the majority of children were described as learning disabled, and were attending schools for children with severe learning difficulties. The likelihood is that these figures reflect the trend for the survival of more multiply-impaired children. This clearly has implications for the screening and assessment of these children.

The population in residential care

A total of thirty-seven percent of the identified population were living in residential care. This finding is partly attributable to the fact that these people form a "captive population", whereas many of the people living in the community were not in contact with the professionals who participated in the survey. Very good response rates were also obtained from residential establishments.

The survey revealed prevalence rates of 7,700 per 100,000 for those people living in residential care; in contrast, Wolf et al.'s (1982) American study estimated a rate of only 754 per 100,000. The figure of 7.7% of people in residential care with dual sensory impairment disguises the fact that over the age of sixty-five, this rises to 8.4%, and for people over eighty-five, the figure is almost 14%. Given the limitations of the methodology, which has a high dependence on current levels of awareness and understanding of sensory disability, this figure is likely to be an underestimate. It is also possible that professionals fail to identify sensory impairments in those experiencing dementia and other cognitive impairments.

Older people living in residential care can therefore be considered an "at risk" population in terms of dual sensory impairment. These findings would suggest the need to improve screening processes, to increase staff awareness about dual sensory impairment and to ensure that those identified get access to appropriate help and services.

The learning disabled population

The total number of adults with learning difficulties was one hundred and twenty-one, two thirds of whom lived in residential care. Although this figure represents 8.2% of the total dual sensory impaired population, two-thirds of all those up to the age of sixty-five years also had learning difficulties.

Given the findings of previous research, this number was much smaller than would be expected. There may be a very good explanation for this. Clinical and functional assessments of individuals reveal much higher numbers than questionnaire methods (Ellis 1986). This may be because questionnaires are often completed by professionals who are largely unaware of the sensory impairments of the people with whom they are working. This hypothesis was supported by the finding in this study that the percentage of learning disabled people who were given "uncertain" vision and hearing status was high, with hearing impairment seeming particularly difficult to assess (31% were described as having an "uncertain" hearing impairment).
This professional uncertainty was also reflected in the Mental Handicap register, where registration is based on a comprehensive questionnaire about individuals. An examination of the register revealed that of 1605 people on the register, only thirty-three were listed as dual sensory impaired. Similarly, an analysis of the returns from long-stay hospital wards, where more multiply-impaired people would have been expected, revealed only twenty-four dual sensory impaired people. Given the inadequacy of standard vision and hearing tests for many in this group, there would appear to be a need to develop skilled expertise to diagnose impairments and undertake functional assessments.

People with learning difficulties should have full access to all the specialist advice and help that is available including any benefits from registration. However, this did not appear to be the case. A much lower percentage of people with learning difficulties wore a hearing aid than did the total population (17% vs. 40.6%); or were registered as hard of hearing (4.0% vs. 24.6%) or partially sighted (6.0% vs. 21.6%). It can further be suggested that the communication needs of dual sensory impaired people with learning difficulties have not yet been adequately addressed. Of the total of 165 people who were identified as having speech difficulties, 70% also had learning difficulties. At the same time, the proportion of the learning difficulties population using Makaton or simple signing methods was very low (10.7%). It is likely that a significant proportion of these people, and the staff working with them, are experiencing unnecessary communication difficulties, and could benefit from appropriate training.

A specialist at the hospital advised me that the staff acknowledged their lack of skill in this area, and often asked for training in communication methods. The people with severe learning difficulties in long-stay hospitals appeared in the past to have been particularly disadvantaged by a failure to address their sensory impairments. However, recently efforts have begun to be directed at remedying this situation. For example, in 1989, a Speech Therapist was employed on a one year project to diagnose hearing impairment in the long stay residents of the hospitals (for further details, see Harrell, 1990). However, it was only possible to undertake full assessments of a small number of people suspected by ward staff of having a hearing impairment.

A Rehabilitation Worker for Visually Impaired People from the Society for the Blind has recently been funded by the Health Authority to undertake functional vision assessments and to increase staff awareness and understanding of visual disability. A hospital-based Clinical Specialist for Profound Handicap and Sensory Difficulties has also recently been employed. These are welcome developments for a particularly disadvantaged group, but it is important that such moves are not made on a piece-meal basis, and that a co-ordinated multi-disciplinary approach is adopted.

It is argued that one of the reasons why the dual sensory impairments of this group of people has not been recognised is that inappropriate use of the medical model has led to them being categorised under the heading of "learning disabled", and has made it difficult for staff to appreciate the real nature of their situation. Staff are primarily trained as specialists working with learning disabled people, and do not necessarily have the knowledge and understanding of multiple disability which would help them work effectively with these people. It would seem that this results in the needs of this group not being adequately met; this is especially true for those dual sensory impaired people.
whose learning difficulties may have been the result of their sensory impairments. Research has shown that a failure to address the needs of this group can result in challenging behaviour; an inappropriate response from service providers, such as the use of medication, leading to a poor quality of life for the people concerned.

"There has been little attention paid to the fact that an individual who is described as "mentally handicapped" may have learning difficulties as a result of being unable to see or hear well. Many of these people have never had a comprehensive test of their vision and hearing. Their needs for care and potential for development, therefore, remain largely unknown. Individual programmes which do not take account of a person's ability to function visually or auditorily may be wasting valuable time and effort unless the sensory impairments are adequately addressed." (Harries, 1991).

The situation in Leicestershire is not unique. A recent national survey of Local Authorities in England and Wales which examined service provision for people with learning difficulties and additional visual and/or auditory impairments concluded:

"Overall, the results reflect a general lack of clarity within Local Authorities regarding the most appropriate ways of defining, assessing need and planning, purchasing and providing services for people with learning disabilities and sensory impairments."

(Hatton and Emmerson, 1994).

The findings would suggest the need to screen this population for sensory impairments, to train staff in carrying out functional assessments, and to give consideration to data collection, planning and the development of policies to address the particular needs of this group. It is further suggested that individual holistic needs led assessments be carried out within a co-ordinated multi-disciplinary approach.

**Minority ethnic communities**

A total of forty-four people from minority ethnic communities were identified. This figure represents 3.1% of the total number of dual sensory people identified. Of these, thirty-eight were Asian. The characteristics of this group were very different from that of the total population. There were more males than females, they were younger and a greater percentage had learning difficulties.

The differing age profiles of the white and Asian population is reflected in these findings, with fewer older Asians compared to the white population. However, it can reasonably be expected that this situation will change, and the characteristics of the two populations will converge.
Registration is the easiest way to gain access to specialist help and benefits. This survey revealed large numbers of unregistered people - three-quarters were not registered as hearing impaired and a third were not registered as visually impaired, yet the functional criteria selected for inclusion in the survey should mean that almost all were registerable.

The majority of people seen by specialist sensory impairment workers were registered. However, there was a distinct trend to be registered for only one sensory impairment; one third of the people identified by specialist workers with visually impaired people were not registered as hearing impaired, and one third of people identified by workers at the Centre for Deaf People were not registered as visually impaired. This is likely to reflect the single sensory approach of these workers.

The percentages of people identified by Health Authority staff who were not registered were very high and may reflect the lack of awareness by these staff of the specialist help that is available. In the case of those known to the Hearing Services Centre, 65% were not registered with the Centre for Deaf People. Only one third of hearing aid users were registered as hearing impaired.

These findings have implications for better co-ordinated systems of working; increased public awareness of the existence of specialist help and advice, and of the benefits of registration. Currently, a significant number of people do not appear to be receiving the help to which they are entitled. Children were particularly disadvantaged by a failure to register (only 8%, for example, were registered as hearing impaired), as were older people living in residential care, and people with learning disabilities.

The need for further research

There is a very good basis for suspecting that the prevalence rate quoted above considerably underestimates the number of dual sensory impaired people living in Leicestershire. There are several reasons for this including the fact that the methodology used in this study had two in-built limitations. First, it depended crucially on the ability of both professionals and public alike to identify dual sensory impairment. It now appears likely that both public and professional knowledge and attitudes towards dual sensory impairment were inadequate for the task.

At the simplest level, not all people who have a significant dual sensory impairment, or their carers and family necessarily recognise this or admit this to be the case, nor will they be in regular or current contact with service providers; in neither case, would they have been included in the questionnaire returns. An attempt was made to avoid these problems by giving clear guidance in a widely circulated user-friendly poster, and by asking for self-referrals. Unfortunately, the number of responses (39) were disappointingly low. There may be a natural reluctance to respond to such requests, and the publicity material may not have been seen or heard.
This study relied heavily on the ability and willingness of professionals to identify dual sensory impaired people. Unfortunately, this may have led to under-reporting and certain kinds of distortion in the figures. There may have been a number of reasons for this. For example,

- the low priority afforded research by busy professionals;
- varying degrees of co-operation and interest;
- pressure of work;
- the existence of a large number of potential older dual sensory impaired people to report upon may have discouraged co-operation;
- some professionals may have been biased to report mainly those people with whom they were currently working;
- others may not have fully understood the nature of dual sensory impairment, despite my guidance leaflet;
- some may have regarded the sensory impairments as a natural consequence of the ageing process, and thus disregarded them;
- others may not have been familiar enough with the level of functioning of the people with whom they currently working.

Additional factors for Social Services staff included the reorganisation that was taking place at the time and the tendency to see the task as the job of the Specialist Social Worker for the Blind.

Some evidence for these biases are reported in Appendix 11, which shows the very different response rates of the different professional groups, who were clearly very varied in their contributions. Good response rates were achieved for residential establishments (Social Services, private, voluntary and health authority) and day centres; however poor response rates were obtained from health service employees, voluntary agencies, ethnic minority groups and the general public.

The second limitation of the research concerns the use of the registers of visual and hearing impairments. Unfortunately, although these registers were one of the very few sources of information which were available, they are known to be unreliable and incomplete (Department of Health, 1988a).

Consulting registers and seeking information from professionals is likely to identify mainly those people with more obvious impairments, and miss many of those with less severe impairments. It is therefore unsurprising that this research identified a high proportion of people with severe and profound impairments, whereas the expectation would be for higher figures for people with moderate impairments (55% of the population were described as having one or both severe vision and severe hearing impairments). It is also unsurprising that the findings reveal a bias towards those living in residential care. (37% of people identified). As a result, the prevalence rate in Leicestershire as measured by this method is significantly less than Wolf et al’s (1982) estimate of 346 per 100,000 in the USA. His figures were based on a combination of data from a number of registers and surveys. But as Wolf admitted, there is a problem in accurately defining dual sensory impairment, which may differ from register to register.
However, even Wolf's higher figure is open to doubt. Epidemiological studies, (e.g. Davis, 1989), which are based on careful sampling, surveys and clinical testing of the population, indicate much higher prevalence rates for single sensory impairments. Other workers have pointed out that there is a positive association between a single sensory impairment and dual sensory impairment (e.g. Schein, 1986); for example, at least thirty-five percent of all blind and partially sighted people experience hearing difficulties even when wearing a hearing aid, and for older people, this figure is likely to be much higher (Bruce et al, 1991). They conclude that:

"Service providers should therefore take the precaution of assuming that elderly visually handicapped people they meet for the first time have a hearing impairment".

It would therefore be reasonable to conclude that there are likely to be many more dual sensory impaired people in Leicestershire than this study would indicate. Clearly, further research is needed in this area, perhaps based on clinical and functional assessments. It would be useful if the Department of Health were to commission this work; another option would be to undertake detailed secondary analysis of the OPCS Disability Survey (Martin et al., 1988) data. Such studies would be a vital check on the validity of the findings reported here.

**Implications for service providers**

In this section, some of the observations made whilst undertaking this stage of the project will be discussed in the light of the findings above. These findings reinforced the observation that professionals often undertake partial assessments of the people they are working with from the perspective of their specialist experience and training. For example, Occupational Therapists tend to focus solely on physical impairments and workers with visually impaired people understandably tend to focus solely on their visual impairment. As was discussed above in relation to people with learning difficulties, this singular focus can result at times in a failure to recognise that consumers of services may have additional sensory impairments. Before this situation can be remedied, three major issues need to be addressed.

**Professionals' attitudes to dual sensory impairment**

The attitudes of professionals in their response to dual sensory impairment were often very obvious. This was particularly marked in the case of older people, who make up the vast majority of the dual sensory impaired population. Ageism appeared to be commonplace. For example, there was a widespread expectation that older people would almost inevitably have sensory impairments; this almost certainly contributed to a failure to recognise the real nature of their disability - which is, in part, caused by these ageist attitudes. Statements that typify such attitudes include "Well she's old, what do you expect?", "She's only got poor eyesight - that goes with old age", "So many have hearing problems we don't consider it", and "Her vision and hearing is adequate for her needs". Visual and hearing abilities do decline with increasing age, but it is argued that this should not mean that older people are deprived of the specialist help and advice that they need. It is important that sensory impairments are diagnosed as early as possible, and that people are given access to help.
Some of the older dual sensory impaired people and their carers who made contact with the researcher were very critical of the unhelpful attitudes of their GP. One severely visually impaired woman who was very concerned about the deterioration in her hearing had been advised by her GP to go home and not to worry about it.

This suggests that an education programme is needed for professionals, which addresses these widely-held discriminatory attitudes.

**An over-reliance on the medical model**

The medical model leads to the categorising of people into distinct groups such as blind, deaf, physically impaired, and so on. Staff are trained to work within these rigid boundaries, and the tendency is to think in stereotypes. As a consequence, there is a danger that the reality of peoples' situation and experience may not be recognised.

This rigid thinking is reflected in the recording systems of the various agencies. These systems often do not allow for the existence of dual sensory impairment or multiple impairment. As a consequence, professionals tend to categorise people according to their own view of the person's major impairment or status. For example, the Employment Services stated in a letter in response to a request for them to assist with the identification process:

"The register our offices maintain of disabled people seeking employment does not identify people with combined disabilities, only the major impairment being recorded for statistical purposes".

A computerised recording system which the Social Services Department had established for Occupational Therapists did allow for the existence of two additional impairments. However, decisions have to be made about which to include, and sensory impairments are often not recorded.

The findings would suggest the need to improve current data collection systems. One possibility could be the establishment of a centralised data base which could include details of all impairments for each individual. This could assist multidisciplinary working and the carrying out of holistic assessments.

**Professionals' lack of knowledge of dual sensory impairment**

There appeared to be a general lack of knowledge and understanding about sensory disability amongst non-specialist workers. Comments such as "I don't know why they've registered her blind - she can see!" and "Oh, he can hear when he wants to, you know" were common. In some cases, this lack of understanding appeared to lead to a failure to recognise impairments.

However this can lead to a denial of peoples' basic rights and needs. For example, one manager of an older person's home, having talked about her special interest in "older people abuse", then proceeded to point out a pile of hearing aids on a shelf. She regarded these as "a nuisance"; she appeared not to
see the importance of them for the people living in the home; and she stated that she "really resented" people who clearly could see being registered blind.

In contact with professionals working with people with learning difficulties, some professionals were observed who considered that if individuals responded to some sounds, and appeared to have some sight, then this was evidence that no impairments existed.

These misunderstandings of the nature of sensory disability by professionals could be addressed by the provision of information and training. One Occupational Therapist who had recently attended a training course on multiple disability remarked on how useful it had been. She now "noticed" if an individual had a vision and or hearing impairment; she had a better understanding of the nature of sensory impairments; she was aware of the local resources that were available; and she said would now record details of the impairments.

It was also clear that even some of the specialists who worked with single sensory impaired people did not appreciate the significance of the effects of a combined vision and hearing impairment. It may be that this is partly due to the historic emphasis on the stereotypical deafblind person, who is unable to see or hear, and uses the deafblind manual to communicate. Debates between professionals about whether someone was "really deafblind" were witnessed. As this study has already shown, there are many more people with lesser degrees of impairment who are likely to experience both communication difficulties and daily living problems. They are neither single sensory impaired, nor conform to the stereotype of the deafblind person.

These fundamental issues - negative attitudes, an over-reliance on the medical model, and a lack of awareness and understanding of dual sensory impairment - may have been some of the reasons which limited the identification by professionals of the number of dual sensory impaired population living in Leicestershire. Until the very existence of dual sensory impaired people is clearly recognised, their needs cannot begin to be met.

More importantly, these issues cloud the understanding of the real nature of dual sensory impairment, which will be explored in the next chapter.
CHAPTER THREE

THE NEEDS OF ADULTS AND OLDER DUAL SENSORY IMPAIRED PEOPLE
INTRODUCTION

In the planning stage of this research, it was decided to focus on the lives and needs of adults and older dual sensory impaired people, about whom there is little information currently available. It was decided to adopt a qualitative approach, in order to allow dual sensory impaired people to speak for themselves about their experiences and needs.

Different need areas were identified, and in the examination of these, the implications for service providers have been drawn out. A final section considers other significant issues for health and social care agencies.

METHOD

The choice of qualitative research

There were several reasons why it was decided to undertake a qualitative study of dual sensory impaired people's needs. Scant research has been carried out into the needs of adults and older dual sensory impaired people, so there is little information available about the lives of this group. The first stage of the study had shown that there appeared to be little understanding amongst local professionals about their needs. A qualitative study would allow for an increased insight and understanding of dual sensory impaired peoples' lives, enable the interviewees to define their own needs and it was hoped give room for them to make proposals for new and innovative services. Such an approach was also in keeping with recent Community Care legislation with its emphasis on user consultation and involvement. Furthermore the group to be studied was a heterogeneous one, the subject complex and the individuals within the group had very varied communication needs such that many required face to face contact with a skilled interviewer. A qualitative approach allowed for the flexibility required. Finally it was considered that a qualitative study would serve to complement the quantitative survey that had already been undertaken.

Selecting a sample

It was recognised that interviewees should be objectively selected but that the rigorous sampling procedures used in quantitative research were inappropriate. As Morton-Williams in Walker (1985) states:-

"Sample design in qualitative research is usually purposive; that is, rather than taking a random cross section of the population to be studied, small numbers of people with specific characteristics, behaviour or experience are selected to facilitate broad comparisons between certain groups that the researcher thinks likely to be important."

In this study the specific characteristics identified for sampling purposes were age and functional severity. A random sample of twelve adults and twelve older people who lived in the community and
who did not have learning difficulties was identified. (The "learning difficulties" group was believed to be a very different subsection of dual sensory impaired people and has been subject to previous study). The sample was stratified by functional severity of both vision and hearing difficulties, thus creating four categories in each age group, viz.:

<table>
<thead>
<tr>
<th>FUNCTIONAL LOSSES</th>
<th>ADULTS 18-64</th>
<th>OLDER PEOPLE 65+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe vision/severe hearing</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Severe vision/moderate hearing</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Moderate vision/severe hearing</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Moderate vision/moderate hearing</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>

Table 20. The dual sensory impaired sample by age and category of vision/hearing difficulties.

The sample included one Asian adult and one Asian older person.

The depth interview and drawing up an interview schedule

The technique chosen comprised individual depth interviews with the sample members using a semi-structured interview schedule. As Burgess (1982) in Walker (1985) states, it provides:

"the opportunity for the researcher to probe deeply, to uncover new clues, to open up new dimensions of a problem and to secure vivid, accurate, inclusive accounts that are based on personal experience" 

A semi-structured interview schedule was drawn up to act as a guide for the interviews. (See Appendix 12) This schedule was informed by an examination of the literature on need and other need surveys of disabled people; discussions with and observations of dual sensory impaired people over the preceding years of the project; and conversations with "experts" and professionals locally, nationally and internationally.

The schedule was piloted with one adult and one older dual sensory impaired person. This enabled the researcher to gain some experience in using the schedule and in undertaking such interviews before commencing with the sample proper. As a result of these interviews further consideration was given to the issue of communication and a decision was made to upgrade the tape recorder.

The schedule was divided into three parts. In the first section, the interviewees were asked to describe the difficulties and restrictions they experienced in their lives, how they tackled them and to speculate about how these could be made easier or overcome. The second section required interviewees to talk about their experience of using health and social care services, their satisfaction with these and how well they met their needs, and to make suggestions about how they could be improved. The third section comprised basic demographic details; further details of their hearing and vision impairments; and information completed by the interviewer about the nature of the interview.
This was very loosely based on work undertaken by Silburn (1987) on disabled peoples' needs and priorities.

The interview schedule was therefore arranged in the following way:-

Part 1. The experience and needs of dual sensory impaired people

- Nature and history of the disability;
- Communication;
- Access to information;
- Personal care;
- Household activities, including shopping;
- Mobility and transport;
- Employment;
- Education;
- Leisure activities;
- Financial situation;
- Social contacts/relationships with others;
- Informal support;
- Dependence/independence;
- Any other concerns;
- General community services.

Part 2. Satisfaction with health and social care service providers

- Health Services;
- Social Services;
- Society for the Blind;
- Centre for Deaf People;
- National Voluntary Agencies;
- Other relevant service providers.

Part 3. Background details (including disability severity rating based on the OPCS Disability Survey functional scale).

A positive advantage of adopting a semi-structured approach was the flexibility it allowed. The schedule was therefore not intended to provide a rigid framework for the interviews. As Morton-Williams in Walker (1985) states:-

"The guide consists of a list of topics to be covered which may be set out with headings with a number of sub-topics that might be posed as questions grouped under each heading. The questions, however, are addressed to the interviewer, indicating the sort
of information he or she should find out; it is the interviewer’s function to devise his or her own questions to introduce topics and then to draw out the respondent by appropriate probes."

All topics were touched upon (where appropriate) but not all were explored in the same depth with all interviewees. The interviewees set the tone and pace of the discussion and were encouraged to raise issues of most concern to them, which were not necessarily included on the original schedule. The reality is that needs cannot easily be categorised in any simple way, and are often interrelated; for example, an interviewee may talk about the difficulties he or she experiences because of inadequate public transport systems when talking about leisure pursuits. The technique allows interviewees to express and explore their needs in terms of their own experiences, rather than by using a structured questionnaire developed from an “expert” perspective.

Earlier in the project the researcher had undertaken a study of the needs of Asian dual sensory impaired people and their carers with an Asian Project Worker, and therefore had some awareness of the issues involved in interviewing people from a minority ethnic community. The literature was consulted on carrying out trans-cultural surveys, (Loner and Bury, 1986) and advice sought from Asian professionals in the field about undertaking these interviews and adapting the semi-structured interview schedule.

Additional items that were covered when talking with Asian interviewees included consideration of cultural, linguistic and religious needs, whether current services were appropriate and accessible, the use of any specialist facilities and services for Asian people, and experiences of racial discrimination.

**Contacting the potential interviewees**

The professionals who had completed the initial screening sheets had been given a guarantee that no direct contact would be made with any individual without their knowledge and consent. A letter was therefore sent to all the professionals who had referred the people included in the sample. Approval to make direct contact was subsequently given in all cases.

Owing to changes in the circumstances of a small number of people in the original sample (such as having recently moved out of the area or into a nursing home), additional individuals meeting the necessary criteria had to be randomly selected. One person was not contacted because he was described as "dangerous" and one older man refused to be interviewed.

A letter was sent to all potential interviewees requesting their co-operation in a face-to-face interview, explaining the purpose of the interview, and giving a guarantee of anonymity. The letters were sent in large print, except in the case of one man who was known to use Braille and was therefore sent a letter in Braille. The letter was sent two weeks before the interview date. One of the interviewees communicated by using a combination of idiosyncratic signs and some British Sign Language signs. Contact was made with her through her mother and she was advised that an interpreter would be employed. The Asian interviewees were contacted on the phone by a Gujerati-
speaking Asian colleague who relayed the details of the letter, and the request for an interview. They were also advised that the interview would be conducted through an interpreter.

Carrying out the interviews

The interviews took place in the interviewees' own homes in February and March 1993. Clearly careful consideration needed to be given to the issues involved in interviewing people who had communication difficulties and also to the issues involved in working with an interpreter. Advice was sought from the general methodological literature on carrying out interviews, but also from specific articles concerned with interviewing Deaf and older people. (For example Baker-Shenk and Kyle, (1990) and Wingrove, (1987). The researcher had undertaken training courses in communicating with deaf and dual sensory impaired people; and had gained experience of the difficulties likely to be encountered both whilst carrying out other aspects of the project and in a previous job.

Actions taken to aid and improve communication included, using clear, concise language, talking in a slightly raised voice, looking directly at the interviewee and keeping the head raised and in full view, ensuring adequate and appropriate lighting, for example sitting opposite a window or by a light, repeating questions, allowing plenty of time for responses, occasionally repeating responses to check understanding and sitting closer than would normally be comfortable. As Wingrove (1987) states:

"Interactions with the old, old suffering from multiple sensory losses may require spatial communication usually reserved for intimacy"

An excellent high quality radio loop system was also used on several occasions with hearing aid users. Interviewees were also always asked at the beginning of the interviews about any particular individual communication requirements they had and these were then observed by the researcher. For example in one case sitting on the person's left side and in three cases using a black felt tip pen when necessary to write questions and comments.

It was recognised that the success of these interviews depended on the ability of the researcher to develop and sustain a good rapport with the interviewees such that they felt able to express their views in a reasonably free manner. Hedges (1985) talks about various strategies that can be adopted to encourage interviewees to expand area of concerns adopting an approach he calls "passionate neutrality"; and stresses the importance of being natural rather than correct. Hoinville (1983) states that:

"the conflict between the interviewer's role as an automaton who will not influence respondents' answers and her role in motivating, explaining, encouraging is particularly exaggerated among interviews with the elderly."
Carrying out these interviews required considerable time, care and attention. The researcher was very aware of the danger of researcher bias, and the need therefore to maintain a balance at all times between objectivity and rapport with the interviewees.

A British Sign Language Interpreter was employed to assist with interviewing the one dual sensory impaired person who used manual communication; and an interpreter for Asian languages was engaged for interviewing the Asian individuals.

It was recognised that additional issues needed to be considered in the planning of these interviews. For example care needed to be taken to ensure that questions and answers were accurately translated and that different cultural values and norms were recognised and respected. Discussions took place prior to the actual interviews to ensure that the interpreters fully understood the nature of the task, the kinds of questions that were likely to be asked and the concepts used, and so on. It was also necessary to advise the Asian interpreter about the best ways of ensuring that effective communication took place between herself and the dual sensory impaired interviewees.

With the exception of the interviews where an interpreter was present, most of the dual sensory impaired adults were interviewed on a one-to-one basis. However, carers were present for five of the interviews with older people. This was due to severe communication difficulties in three cases, such that assistance was required; and owing to two women stating that their husbands had mental health problems and that they therefore needed to be present. One woman adamantly refused to allow the researcher to speak to her husband alone. She stated that he was a paranoid schizophrenic and could not be trusted to tell the truth. These third parties did provide some assistance with communication but clearly the presence of these other people could have had a restrictive influence on the responses given by the interviewees.

At the beginning of each interview, interviewees were asked about their particular communication needs, and requested that they indicate if at any point during the interview they failed to understand. All the conversations were taped. It was not possible to make notes during the interviews given the concentration required to enable effective communication to take place. None of the interviewees however appeared to be inhibited by the presence of the microphone. The majority of the interviewees were seen once only, but in the case of four people, two visits proved necessary. Interviews varied in length from one hour to two and a half hours. At the end information and advice was sometimes offered in response to issues raised and referrals made to service providers.

The analysis

The tapes were transcribed following the interviews and together produced 560 pages of manuscript. A small number of the interviewees had speech difficulties, such that the tapes were not totally comprehensible to the secretary undertaking the task; the sections of these tapes were transcribed by the researcher. The transcriptions were checked against the tapes and then coded according to a variety of categories, broadly based on the original interview outline. An analysis was then conducted on the basis of these categories and the basic elements of experience common to the interviewees drawn out.
Comparisons were made between two groups - the adults and older people. It was decided at this stage to discount one of the interviews with an older person, as her vision had been restored a few years previously by an operation. The following analysis and interpretation is therefore based on a sample of twenty-three, comprising twelve adults and eleven older dual sensory impaired people. Caution clearly has to be exercised when generalising from such a small sample of people. However, considerable faith can be placed on the representativeness of the adult sample, who comprise approximately a quarter of the total adult population identified, excluding those with learning difficulties.

A profile of the individuals comprising the sample is provided in Appendix 13. All the people interviewed have been given fictitious names. Their comments have been reproduced exactly as spoken in the interviews.

**INTERPRETING THE FINDINGS**

In the following pages is a description of the needs of dual sensory impaired people which arise from the interaction of the individual with impairments and the societal barriers which impede their full participation in society. The findings have been presented under the following headings:

**The experience of dual sensory impairment**
- The characteristics of dual sensory impaired people
- Education (adults only)
- Communication
- Communication needs
- Mobility and transport
- Employment (adults only)
- Personal care and household activities
- Finances
- Social and leisure activities
- Support from others
- Emotional needs

In this section, the implications arising out of the needs have been identified as they occurred, and are discussed in context.

**Current health and social care service provision**
- The Health Service
- Social Care Services
- Co-ordination between service providers
- National voluntary agencies
This section is a description of the interviewees' current levels of satisfaction with the above.

**Wider implications for health and social care service providers**
- Improvements to mainstream health and social care services
- The development of new, local specialist resources and services
- The adoption of a new empowering approach to service provision

The general implications for these agencies are drawn out under these three main headings:

**The experience of dual sensory impairment**

**The characteristics of dual sensory impaired people**

Clearly age is a very significant factor in dual sensory impairment. As Stone (1987) recognises:

"In the elderly, the sensory losses must be viewed as part of a constellation of physical and psycho-social losses commonly seen in the later years. As compared to the younger age group, losses are more prevalent and often of greater magnitude: loss of spouse, loss of income, loss of home, loss of health, and the like.... Moreover, these losses occur during a time in life when human and material resources are dwindling."

For that reason, two distinct age-groups of interviewees were identified, and the similarities and differences between them and their experiences have been drawn out in subsequent sections. In this study interviewees under the age of sixty-five years are referred to as adults, and those over sixty-five years as older people.

The majority of the disabled adults who were interviewed had some residual hearing and sight, and used speech, although a small number of the interviewees had speech which was difficult to understand at times. Susan Howard was the one exception; she did not have speech, and used a mixture of British Sign language and idiosyncratic signs to communicate with others. Approximately half of the adults had additional chronic health problems or impairments; for example, multiple sclerosis, arthritis, angina, kidney problems, a weak lung, a heart condition and so on.

The majority of them had experienced at least one sensory impairment from birth or early childhood. However, nearly all of them were experiencing an ongoing deterioration in one or both senses.

Andrew Duncan, for example, had experienced a deterioration in both senses over the years. He was born with no sight in his right eye and partial sight in his left. He remembers not hearing very well as a child, and being called "cloth ears".

"It seems such a cruel process that you get adjusted to what you can do and what you can't do, and then the thing gets a little bit worse all the time, sort of thing."
Several of the interviewees appeared not to have been aware of the gradual deterioration in their senses; or it may be that some chose to ignore it and had therefore not sought medical help.

Alan Woodger was born partially sighted and partially deaf. On leaving school he had worked in various factories and had not paid much attention to his sight and hearing. A few years ago he was on a Government Training Scheme when he was observed to be having difficulty seeing to do his work. He was referred to the eye clinic of the local hospital and subsequently discovered that both his eyesight and hearing had deteriorated significantly.

"I've got two hearing aids on now which is the powerfullist the hospital could give me. They said they can't give me anything more powerful. He said if these won't help you I'm afraid you'll have to learn sign language because you won't be able to hear. I'm like that I'm on borrowed time. Same with my eyes. If my right eye goes like my left eye I'd have to feel my way through that door."

Four of the adult interviewees had experienced congenital or early onset hearing impairment and had subsequently developed "tunnel vision". It is likely that they also had a congenital visual impairment which would result in a gradual deterioration in their vision. Susan Howard and Henry Cramer had had their visual difficulties identified at school when they were teenagers; however, Christine Bell's impairment was not diagnosed until she was in her fifties, and Donna Philips' when she was in her forties.

In contrast, most of the older interviewees were born sighted and hearing, and developed impairments in later life. Like the majority of the adults, they relied on residual hearing and vision, and all but one had speech. The exceptions were one woman, Sarah Miles, who had a severe hearing impairment from birth or early childhood, and Bill Broadhurst who was born with a dual impairment.

Most had additional chronic illnesses or disabilities associated with ageing. A small number were described as experiencing confusion and memory loss, although the cause of this may lie with their dual sensory impairment. As Wolanin and Philips (1982) stated:

"Often when an older person appears confused, disorientated, and unable to answer questions quickly enough, the actual problem is related to impairment of vision or hearing."

Some had experienced one sensory impairment a number of years ago and in recent years experienced a second, whilst others had experienced a decline in both senses during the last few years.

Many of the older interviewees regarded their impairments and health problems as a natural consequence of ageing.

"As I say, I'm getting on a bit and I mustn't expect too much". (John Palmer)
"Well it couldn't be improved because of my age. What I get I've got to expect. Aches and pains." (Molly Richardson)

"She really isn't very bothered about not hearing or about her sight. She's just living her life because she has to and she's alive. So she is living her life but she is quite OK the way she is. I mean, she doesn't moan about the fact that she can't hear or can't see very well. I think that she has accepted it; that it is bound to happen because of her age." (Saroj Mehta, daughter of Manju Metha)

The reality for virtually all interviewees was that they were experiencing a gradual deterioration in one or both senses. In addition, the majority of the interviewees were not simply dual sensory impaired, but were experiencing multiple impairments. This, like the evidence presented in the previous chapter, again challenges the stereotypical view of deafblindness.

**Education**

Only the adult interviewees were asked questions about their childhood education. It was considered important to ask them about their earlier educational experiences, given the influence of these on their subsequent life experiences. The majority had attended a Special School for either Deaf or blind/partially sighted children for part or all of their education. Several expressed dissatisfaction with the schools that they had attended, some felt that their needs as dual sensory impaired children had been ignored, and some clearly felt that they had been disadvantaged early in life by the inadequacy of their education.

For example, Janice Masters had attended a school for partially sighted children. She felt that her education had suffered because no account had been taken of her hearing impairment.

"I don't know if they have schools for partially sighted and partially deaf children because you need to be near a blackboard but you've got to be able to hear the teacher at the same time.... You miss out on a lot when you're at school."

Janice was now actively trying to assist her own children in learning to read and write, but was frustrated by her own limited vocabulary.

Alan Woodger also felt that he had not had his educational needs met. He was born both vision and hearing impaired and attended an "ordinary school" until he was fifteen years old. He used to have to sit at the front of the class because he could not easily see or hear what was going on. He was sent for an "extra year" at the age of fifteen to a Special School for partially sighted children.

"I was losing out. They were learning a lot quicker at an earlier age than me which put me behind as I got older."
Some (Donna Philips, Susan Howard and Henry Cramer) had attended schools for Deaf children, where the emphasis appeared to have been on oral methods, teaching children to lip-read and speak, as opposed to learning sign language. Donna picked up sign language in the playground, but has subsequently rejected contact with the deaf community, choosing instead to rely on her speech and mix with hearing people. In reality, her speech was quite difficult to comprehend, and she seemed frequently to misunderstand what was said to her.

"When I was a kid, right, I wouldn't talk to someone. I was frightened. I ran away from school and went home to me Mum and Dad. I was frightened. So that's why I couldn't hear it very well. Mum and Dad took me down the boarding school in .... See if I like it there, you know. I like all the kids. Some of them like this their hands. (Does some signs with her hands). It was only a little while after that I forgot it. I thought I speak very well and that's it."

It can be speculated that this traditional oral educational approach has had two effects, one of which are also true for Deaf people. First, it can be said to deny people the opportunity to become part of the Deaf community, with their own language (British Sign Language) and culture.

However, for Donna and other dual sensory impaired people, the oral method has had a second effect, reducing their ability to communicate effectively with everyone. An inability to sign eliminates a means of communication which may be used even when sight deteriorates; strategies such as "hands-on" signing can be used by people with reducing vision to continue to use sign language. There is an expectation that when people develop a severe dual sensory impairment, they can be taught to communicate using the deafblind manual. However, their lower literacy levels make it very difficult for people born with a severe or profound hearing impairment who later lose their sight to use this communication method, which depends on spelling out words on the hand. Total communication methods of education may therefore be best for dual sensory impaired children.

It appeared that some of the people in this study failed to have their vision and hearing impairments identified when they were children. This would suggest the need for improved screening, particularly of single sensory impaired children for early signs of a second impairment. The experience of some of the interviewees would further suggest the need to ensure that whatever type of school a child attends, full account is taken of his/her dual sensory impairment and that teachers receive adequate training in this area.

1. Higher/Further Education

Only one of the interviewees, Janice Masters, talked of attempting to pursue her education in later life. She had joined a computer class run by the WEA for "slow learning people"; she had decided to attend this group because the class was small, comprising seven people, and the teacher was able to give the students quite a lot of individual attention. Janice did not feel confident about joining an ordinary evening class. She did not think that the teachers would meet her communication needs:-
"I think they should make people with disabilities more welcome. Sort of advertise. Because you know at night school, I'm pretty deaf at night school. I couldn't go to night school because it's like I wouldn't be able to hear what the teacher was saying. I wouldn't be able to see what she was putting on the blackboard or whatever."

She felt that there ought to be small classes created specifically for disabled people like herself, but also that disabled people should be actively welcomed and encouraged to join educational classes. The teachers would need to be more aware of disabled people's needs, and be prepared to give these students a little extra time. Clearly, educational establishments need to consider how best to ensure opportunities for dual sensory impaired people to continue their learning.

Communication

It has been argued that a person's sense of their own individuality and autonomy depends crucially on their ability to communicate with others.

"After the need for survival, the need to communicate is the most important in the human needs hierarchy, and probably differentiates the thin line that separates the 'person from the non-person state'". (Bernardini, 1985).

The majority of the dual sensory impaired people interviewed in this study had some residual sight and hearing. However, they experienced distorted visual and auditory information from which they had to try to construct an understanding of the world around them. Their limited ability to understand what was going on was one reason why they had difficulty in communicating with other people.

However, communication is a two-way process, involving both the sender and receiver of messages. In the following, it will be argued that the responsibility for meeting dual sensory impaired people's communication needs lies both with sighted and hearing people's response at an individual level, and with society at large.

1. Face-to-face communication

There was diversity, both in the difficulties experienced and in the needs of the interviewees in respect of communication. The majority of them relied on speech and used residual sight and/or hearing to communicate with others, although the speech of some of the interviewees was not always easily comprehensible. Only one of the interviewees was a profoundly Deaf sign user, and although she understood some signs, she was not proficient in British Sign Language; one interviewee used the deafblind manual, but that was only very occasionally.

A minority of the older interviewees showed a reduced ability to process information. Carol McPherson, for example, found it frustrating that she would forget what she was saying half way through a sentence. In consequence, communication with these older people needs to proceed at
a slower and more gentle pace; those who show some mental confusion may rely heavily on a third party to communicate on their behalf.

Some of the people with severe impairments had difficulty communicating with others on a one-to-one basis, even in ideal environmental conditions. John Brown, for example, was profoundly deaf and a good lip-reader until he became blind a couple of years ago. He had a very small amount of remaining vision. As a consequence, lip-reading others was now virtually impossible, but he could sometimes understand his wife. People talked to John by writing in large print on a pad. He then used a magnifying glass to painstakingly read what had been written. A conversation carried out in this way is slow and laborious, and loses much of its spontaneity. When it came to meeting friends, John said:-

"You just feel lost. I can't converse with them so my wife tells me and then I can join in a bit, but it's very brief. I just sit down and they just talk amongst themselves. So if we're out and we meet friends, well I don't know what they're saying. My wife tells me afterwards when we come home. I can't converse with them, not now. I could before because I could see them."

It had been suggested to John by a Social Worker and Rehabilitation Worker that he learn the deafblind manual. However he had not been very keen to take up their suggestion.

Christine Bell was born severely hearing impaired and had lip-read most of her life; her vision had now deteriorated to such an extent that she was no longer able to see people's faces. She found it extremely difficult to understand what other people were saying to her, and holding a conversation was a real struggle, both for her and the speaker. She had recently been taught the deafblind manual, and was using this occasionally with her daughter and Home Carer when she was "stuck". She asked people to sit close to her and to repeat things.

Communicating with others was extremely difficult for her even in ideal conditions such as on a one-to-one basis in a quiet room; and it became almost impossible when she went out to social groups or a day centre, where scant attention was paid to her communication needs. Consequently, she was extremely isolated, and often unaware of what was going on in her immediate environment.

Susan Howard was another interviewee who was also very isolated. She used a mixture of British Sign Language signs and idiosyncratic signs and gestures which she had developed with her mother. She was unable to understand speech, and also had difficulty understanding British Sign Language. She lived with her mother in a small village and rarely communicated with anyone else. She stated that this situation made her feel "depressed". She was heavily reliant on her mother to communicate with others on her behalf.

Environmental conditions were a crucial factor in communication for most of the dual sensory impaired people interviewed; for example, it was more difficult for them to lip-read in a poorly lit room or when the source of light was behind the speaker.
Donna Philips, for example, who had "tunnel vision", now had to position herself such that the face of the person she was conversing with was within her restricted field of vision "in order to see to hear it".

"I can't lip-read very well, although I've been lip-reading for fifty years.......because I can't see that well." (Edna Gash)

"I used to be a very good lip-reader but of course it's awkward now." (Molly Richardson)

It was interesting to note that the researcher was often asked by the interviewees to sit in a particular seat during the interview which was in the best position to meet their communication needs.

Traditionally, people with a hearing impairment are issued with a hearing aid, with the expectation that this will improve their communication abilities. This was not necessarily the case for those who were interviewed in this study, although many used hearing aids. The age of the interviewee seemed to be an important factor. Most of the adults were hearing aid users; their reactions were largely positive. Most regarded them as an absolutely essential piece of equipment which they could not do without, although a few found them unsatisfactory and difficult to get used to. Several of the interviewees had been prescribed aids from a young age, and could hear nothing or very little without them.

"When I take it off I can't hear anybody. I can't hear the door. Nothing." (Donna Philips)

In contrast, approximately half of the older interviewees did not use the hearing aids they had been prescribed, as has been found in earlier studies (e.g. Kaplan, 1985). The reasons for this were varied, including, for example, not wanting to acknowledge their hearing impairment, finding it hard to discriminate speech, difficulty in using the aid, finding it uncomfortable, a dislike in using it in noisy surroundings, and problems in obtaining batteries.

Bill Broadhurst, for example, gave the following reasons as to why he did not use his aid:-

"It's right loud and if they're all speaking then you're picking all the sounds up. It's gobble, gobble, gobble like Donald Duck. If I go in the kitchen and they're all speaking, someone starts shouting and the dog barks, it goes through you. And that's why I don't wear it."

"I think a hearing aid is dangerous if you can't see. Because you might have leaves or wind blowing and the noise of the traffic, even though you're only using one ear, and you're not right good in the other ear, you're better with your hearing aid out and listen for the quietness."
He also expressed frustration at the difficulty he experienced in obtaining hearing aid batteries; it involved an expensive taxi ride from his village to the hospital in Leicester.

"The thing is when you want new batteries you are supposed to go to the hospital to get them, and I'm very bad at travelling a big distance."

Bill wondered why batteries could not be given out on a monthly basis to the hard of hearing people who attended his partially sighted group, or be made available on prescription from chemists.

The majority of interviewees had been issued with a single aid, despite the fact that visually impaired people are recommended to wear two aids to improve their ability to locate sounds (Heyes, 1981, 1982). Janice Masters had recently been accepted for guide dog training and had been advised to obtain a second aid. Sound localisation is important for safe mobility, but even more so for effective communication. In situations where more than one speaker can be heard, or in noisy environments, the ability to localise and attend to the position of the speaker is vital. This will be particularly true if the listener cannot easily see the speaker's lip movements. Dual sensory impaired people may experience difficulties on both counts.

In fact, most of the interviewees found it extremely demanding, if not impossible, to communicate with more than one or two people at the same time. They preferred a one-to-one situation. This meant that they often missed out on conversations between friends and family and felt "left out".

"If there's more than one person it's hopeless. I can talk to somebody face-to-face, but if somebody else starting talking, well it's hopeless. I can't get that at all." (Janice Masters)

"If people are speaking normally I probably wouldn't, with the conversation flowing back and forth, I'd pick up bits and bobs of what they are saying but not the whole conversation." (Andrew Duncan)

"I miss a lot. I feel left out. It's like when I went to my niece's wedding. I just sat down and let them get on with it. It's too much of a strain, put it that way." (Hazel Simpson)

"The only difficulty he finds is if people are talking. Talking and he doesn't like it. He thinks when will they go, leave?" (Interpreter for Ram Pancholi)

With this degree of difficulty in a small, family group, communication in larger groups was understandably almost impossible. As a result, interviewees might attend an activity or group, and yet not be able to participate at all.

Even in common, everyday environments they found it difficult to communicate with others. Situations where there was a lot of background noise were disliked and sometimes deliberately avoided. These included places such as streets with traffic, public houses, restaurants, supermarkets with background music, offices, public transport, places with air conditioning and so on.
"I've got to the stage now where, I didn't used to, but I'll avoid certain situations where I know that I'm going to be at too much of a loss with the sight and hearing, that sort of thing. Like a noisy pub or a disco, or a noisy event with a lot of people coming and going.... I mean if you can't see faces and see people around you in the whole. It's just the noise level. You're not picking out individual conversations. It just gets so frustrating I feel just like standing up and storming out of the room you know, because you can't give what you've got to offer, can you?" (Andrew Duncan)

"The street noises cause me a lot of hassle. I can't hear the person who is alongside me trying to talk to me." (Philip Hammond)

"That's another problem. People have said hello to me. I only know that they have said hello because the boys have said something. 'That lady over there has just said hello to you mummy'. I then just say hello. I don't know who it is. Or if people are shouting at me. It's no use shouting me in the streets. I wouldn't know where you've shouted from. I wouldn't know where to look.... I go around town a lot of the time with my friend and she sees a lot of people that she knows and I know. But they talk to her most of the time because I'm very quiet. I don't know what they are saying anyway most of the time, and I don't know who it is." (Janice Masters)

Both Janice Masters and Alan Woodger talked of their frustration in trying to discuss their benefits at the DSS office. They both experienced great difficulty in understanding the staff, who were speaking behind glass partitions. In the past, Alan Woodger had become very frustrated with the attitude of the staff, and lost his temper.

"I hate going down there. The background is so noisy. Obviously with people and children and they've got these screens there.... I'm tip-toeing so that I can get the voice coming into the microphone but it's impossible." (Janice Masters)

On one occasion, Janice resorted to asking the man behind the counter to write everything he had said down in a letter and send it to her. She had had no idea what he was saying. She felt difficulties in communicating with others was her biggest problem:-

"I feel that's the worst, that's what affects me most, coming into contact with people. Because you're coming into contact with people everywhere. They could be saying something really important to you."

The reality is that communication involves two people. The dual sensory impaired interviewees felt that the behaviour of others often makes face-to-face communication more difficult. For example, they reported that people often talk too quickly, too quietly or too loudly; do not face them when they speak; fail to ensure that they are made aware of what is being discussed or of any changes in the topic of conversation; and feel uncomfortable with their need of the disabled person to behave in slightly unusual ways, such as looking closely at the speaker's face. In undertaking the interviews,
the researcher was critically aware of the above factors, always asked people what their individual communication requirements were, and endeavoured to take account of them. Some of the interviewees commented on the relative ease with which communication proceeded; this was not always their experience with others.

These findings suggest the need to improve other people's knowledge and understanding of the effects of dual sensory impairment and to improve their communication skills.

However there would also appear to be a need to challenge and change attitudes. The interviewees experienced negative, patronising and disempowering attitudes, characterised by the "does he take sugar" approach.

Some of John Brown's friends no longer talked to him. He believed it was because of their reluctance to write in large print rather than speaking.

"Someone came here at Christmas and he had a letter for us. You see it was for my husband as well, and I said 'come in'. He was just turning his car around. 'Oh come on in a minute'. He said 'I was just writing a letter, it's no use coming in because he can't hear me can he?' You see, that is the attitude of people." (Wife of John Brown)

Like John, Christine Bell found some people were understanding and would try to converse with her, whilst others she knew deliberately avoided her:-

"These people, they probably don't understand it and they think rather than be embarrassed, they'd rather not be involved. I've even got relations who don't contact me very often."

The consequence of this breakdown in communication with others was that many dual sensory impaired people simply withdrew from social contact beyond close family and friends.

"That's what I'm afraid of. I don't like going out to meet people. I think I've got a bit of a phobia about it. It's being deaf, and I mean some people do make fun of you, you know, and it's very hurtful and you sort of get in your shell." (Molly Richardson)

"I think that if I could hear I would probably take more interest. But I can't converse with people you see, so there's no point is there? I mean I don't know what they're saying." (John Brown)

Yoken's (1979) study described withdrawal and isolation in deafblind people.

"Isolation is an unavoidable reality in the lives of deafblind people. For most, the loneliness and isolation is massive and unrelieved. One theme emerging from the interviews is the relationship among rejection, withdrawal and isolation. One way
that people deal with rejection, obvious or subtle, is to avoid the contact that makes it possible."

This was also noted by the Norwegian study of deafblind people, which highlighted the isolation experienced by dual sensory impaired people, and their restricted opportunities to participate in activities beyond their home environment.

"The data seem to indicate that the deafblind person's contacts are to a great degree restricted to the persons who live in the house where he lives, that is to say his family or his institution employees. Contact outside the immediate physical milieu seems to be difficult to establish or maintain." (The Health Services of Norway, 1976/77).

Such severe isolation can have serious ill-effects on mental health. For example, one of the consequences of being cut off from stimulation can be the development of hallucinations, and one of the interviewees stated that they experienced these. Studies have been carried out on the deleterious effect of sensory deprivation on mental health. Slade and Bentall (1988), for example, found that hallucinations are common among people who are isolated for long periods of time, especially under stress. Sauerburger (1993) suggests that the hallucinations experienced by some dual sensory impaired people could be symptoms of the isolation and sensory deprivation they experience, which is intensified by limited physical movement. She argues that what people need is improved communication with others, and to engage in meaningful activities.

2. Written communication

The majority of the older interviewees and several of the adult interviewees relied totally on someone else to deal with written correspondence on their behalf. There were various reasons for this, in addition to their visual difficulties. These included lower literacy levels in some congenitally deaf people; a cognitive impairment in some of the older people; the lack of provision of aids and difficulties experienced when using them; and the failure to meet the written communication needs of dual sensory impaired people by using appropriate formats, such as large clear print or Braille.

A significant group of adults who had been hearing impaired since birth had limited literacy skills. Henry Cramer, for example, stated:

"I'm not very good at writing. I'm pretty terrible at spelling. Not very good at that. I don't mind writing but I'm not very good at making sentences. I just do the best I can."

Some used low vision aids to see the printed word, but success with them appeared to be variable. For John Brown, they were an essential lifeline, and he repeated on several occasions that life would be "pretty grim" without them; he kept a box of them by his side. Others, however, did not use them, and/or found using aids hard work and tiring. Bernard Oakley, for example, attempted to read his letters by using low vision aids, but found it slow and hard work.
"No, you're not enjoying it. You're straining all the time. The paper is bad enough. Takes me a full day. I read a little bit and put it down. It's still a struggle."

Paul Ward relied on his wife to deal with all his letters and bills, because reading was such a slow, tedious business for him.

"It's going along the line then finding my way back to the next line again. Sometimes I miss a line or go back onto the same line.... Then after a while my eyes start running and I get fed up with doing it."

In addition, printed material was often of such poor quality that it rendered aids of limited use. Christine Bell had an Eezee Reader on loan from the Society for the Blind which enabled her to read her own correspondence. It reproduced the printed matter on the television screen in large letters. However, she often received letters and bills which she was unable to read because the print was too small and faint. Philip Hammond used a computer with a voice synthesiser at work to read his correspondence, but it would reject all letters that were poorly printed.

Some of the interviewees highlighted their need for letters and information to be produced in formats which were accessible to them; for example in clear, dark and large print, and in one case, Braille.

"I would say that Electric people, any standard people who send bills, they should do better by thinking of ideas of bringing larger print out for people. Because a lot of bills are far too small for people who have eyesight problems." (Alan Woodger)

Janice Masters was very critical of the letters which she had received from the hospital.

"A lot of the time you know you get letters from the hospital where it's grey writing on white paper. It's not black writing on white paper, it's grey, and sometimes I use the magnifying glass and I still can't see it. So I tend to wait till I'm in contact with another adult and ask them to read it for me.... If I've got an appointment card you never know it might be for the next day, and I might not even see anybody. So these sorts of things are really important."

She felt that the eye clinic should send out letters to people in large print. She wondered if it was her responsibility to let other companies know that she needed her letters in this format or whether the Society for the Blind could "point this out at a conference".

Andrew Duncan had been taught to read and write Braille at school. He was now very grateful for this skill. Although he received some information in Braille, for example the TV Times, most letters and bills were sent to him in print, and in consequence he had to seek assistance from his mother.
3. Access to information

People who have sight and hearing gain access to information about the world around them in a variety of ways; directly, by observation and by listening to others individually or in groups, and indirectly, through media such as newspapers, the radio and television. We all depend on a flow of information to enable us to remain aware of our environment, to have meaningful interactions with others, and thus participate in society. Dual sensory impaired people, however, can experience difficulties or be unable to gain access to information through the media, as well as more directly through contact with others. As a consequence, they can become isolated from the ebb and flow of life around them.

For example, Bill Broadhurst, who had been dual sensory impaired from birth, described how he had felt left out all his life, as other men talked about such topics as sporting events which they had seen on the television or read about in the paper. This had led him to withdraw inside himself.

"They read the paper and they're talking about it, maybe at night. They say did you see, so and so, and they're talking about stuff like that, you see such as results. So I think in being my own little self, you know."

Christine Bell's only method of receiving information about the world around her was to struggle to make sense of what another person was saying to her. She really missed "contact" with the world through the television:

"I do wish I could follow what they were saying. And then you see it's a topic for conversation isn't it? If you can't follow what they're talking about and you can't read the papers very well...what can you do?"

Older dual sensory impaired people and those with severe impairments in particular appeared very dependent on others for gaining access to information. They therefore required personal assistance.

The difficulties of others could be ameliorated by ensuring that information is presented in appropriate ways. Newsprint, for example, is too small to be read by many people with a visual impairment. Janice Masters had recently been given a copy of a new large print newspaper. She was really pleased with this and felt that this paper would enable her to be better informed about what was going on around her. As a consequence, she intended to order it on a regular basis if that was possible. As mentioned in the previous section, low vision aids can be very important for dual sensory impaired people. Christine Bell had recently been provided with an Eezee reader which enabled her to read news items in large print (Snippets) which were provided by the National Deafblind League. She was extremely pleased with this aid, which had given her access to information which she had previously been denied.

Another important source of information is the television; the majority of the interviewees had one. However, most found it extremely difficult to get maximum benefit from it. Some described sitting
up close to the set to try to see the picture and of having to concentrate very hard to understand it, and/or having the volume turned up very high, which caused distress to other members of the family.

"I can't see the television very clear and I can't follow what they are talking about very well. Occasionally I pick up the odd word or two." (Christine Bell)

"Sometimes I hear the people talk and don't understand what they're saying." (Henry Cramer)

"I can't watch television very much because I can't see it. Owing to the deafness and blindness, I can't see the television. I can hear the noise but I can't hear the words of the people, you see. I get a couple of words now and again, but not enough to make any sense, sometimes. But it's no use turning the volume up, because I can hear the noise but I can't put the words together." (Carol McPherson)

"When you get programmes you're familiar with, or news items or whatever, you find you can piece together between the sound and what little picture you pick up." (Philip Hammond)

Interviewees said that it was very important that the speech of the people on the television was clear and that background noise was minimised. Hazel Simpson found it easier to watch old black and white films as in these films there was no background noise and the actors and actresses tended to speak loudly and more clearly.

Subtitles were also helpful for some people, but they needed to be left on the screen for a longer period of time:

"When I've got halfway through the subtitle it's gone, so sometimes I can't be bothered with it, I'm a bit disappointed about that. They should leave it on the screen a little longer." (Janice Masters)

Both Molly Richardson and John Brown used teletext. However, John Brown only managed to "pick up" fifty percent of what was written on the screen. He also suggested that more time should be allowed for people with visual difficulties to read the screen.

As a consequence of these difficulties, several appeared to derive little benefit from their television, and a couple of the interviewees had the television on purely "for company". This could easily be addressed by making some relatively minor technical changes which would greatly improve dual sensory impaired people's access to broadcast information. For example, on-screen text is provided only for a limited number of programmes; this could be extended to all programmes, and it may be possible to slow it down. The use of a loop system could allow some dual sensory impaired people access to improved sound quality, whilst also permitting hearing people to listen to the television at a normal volume.
There would appear to be a need for more widespread awareness of the existence and benefits of aids such as these. Several of the interviewees had never heard of the existence of loop systems, and only two of the interviewees (Alan Woodger and Janice Masters) actually had one. Their use, for some dual sensory impaired people, could extend to radio and tape-recorders, giving them access to both broadcast and taped information, such as talking newspapers and books.

Communication needs

Unfortunately, the difficulties in communicating which dual sensory impaired people face are greatly compounded by the failure of others to consider their communication needs. For example, the failure to use appropriate communication skills, techniques and sign language; to provide interpreters and human aids to communication; to supply essential aids and equipment; to create suitable environments and to ensure that information is provided in appropriate formats.

It is argued that this failure to address dual sensory impaired people's basic communication needs has had serious detrimental effects on their quality of life. For example, it has resulted in dual sensory impaired people lacking knowledge of what is going on in their immediate surroundings or in the wider world; it has forced them to rely heavily on carers to communicate on their behalf with others; it restricts or denies them access to community facilities; it leaves some lacking stimulating and meaningful activity; it limits their contact with others beyond close family or friends; and, perhaps, most important of all, results in people experiencing severe and enforced isolation, even in the company of others.

To fully meet the communication needs of dual sensory impaired people, it is suggested that a multifaceted approach be adopted. This would include interventions which focus on minimising the effects of individual impairments, but which also encompass environmental and societal changes.

1. Regular assessment of vision and hearing

There would appear to be a need for dual sensory impaired people to have regular medical checks of their sight and hearing, and to be fully advised about the diagnosis and prognosis of their condition/s. It is known that older people are more likely to accept sensory impairment as a consequence of ageing, and are therefore less likely to seek medical help. There is a need therefore to encourage older people to take advantage of the help and services that are available as early as possible. Clearly carers and professionals also need to be aware of the importance of early identification, and of the consequences of a dual sensory impairment.

2. Improved provision of aids and equipment

It is important that dual sensory impaired people are enabled to make the maximum use of any remaining sight or hearing they may have. One answer is the provision of aids and equipment which help to minimise the effects of their impairments. The majority of interviewees were hearing aid users. However, as has been discussed above, consideration should always be given to the provision of two hearing aids for dual sensory impaired people, which are vital to enable them to locate sounds.
and speech; only two people in this study had been issued with two aids. Many were also not aware of their entitlement to spare aids.

A significant number of the people in this study did not use, or were not aware of the other kinds of aids, such as radio loop system, in-built loop systems, low vision aids, Eezee readers, and computers, all of which have the potential to improve their ability to communicate effectively and to regain or retain their independence. For some, for example John Brown, they may provide an essential lifeline.

The radio loop system which was used to communicate with several of the interviewees greatly assisted communication. By allowing the interviewee to receive a better quality of sound, the researcher's speech was easier for them to understand. Not only is such equipment useful in one-to-one communication, it was also the researcher's experience at the Society for the Blind that the system enabled some previously isolated people to participate in group settings. The reality was that none of the interviewees had access to, or awareness of this particular piece of equipment. The researcher observed one dual sensory impaired man in Denmark using such a "one-to-one communicator" very successfully, but have never seen it in use in Britain.

Only a minority of those interviewees with residual hearing had telephones adapted for people with a hearing impairment; others attempted to use standard telephones with varying degrees of success. Alan Woodger felt that telephones were essential pieces of equipment for people who had restricted mobility, and that British Telecom should provide more assistance to disabled people, particularly in reducing the cost of calls. For Edna Gash, one of the older interviewees, the telephone was the main way she managed to keep in contact with her friends, who had themselves developed chronic illnesses and disabilities and had become house-bound.

Most people, however, were unaware of the possibilities which exist for improved telephone communications. It is likely that more could have gained access to this method of communication if they had been aware of the existence of appropriate modifications, and been provided with the necessary equipment. Even so, some, like Paul Ward, for example, were quite happy to let their carer use the telephone on their behalf:-

"There's a lot of times I answer the phone to people and it's just muffled. I can't understand what they're on about because they don't speak clear. It depends who speaks."

This underpins the need to give people choices, rather than impose solutions upon them.

The majority of aids currently provided for dual sensory impaired people are designed with single sensory impairment in mind, and are issued by professionals who specialise in working with either visually impaired people or hearing impaired people. Some of them are unaware of the particular needs of dual sensory impaired people. For example, one professional working with hearing impaired people advised the researcher that the use of a radio loop system would be counter-productive, acting as a "barrier to communication". His thinking appeared to be influenced by a
belief and expectation that hearing impaired people would have good vision; for him, communication had therefore to be achieved by either lip-reading or signing.

Janice Masters had been issued with a loop system by a professional from the Centre for Deaf People who showed no awareness or understanding of her dual sensory impairment. The wiring system had been explained to her, but she was unable to distinguish between the colours of the different wires, and the instructions were in standard print so she was unable to read them.

"You get something from the Deaf. They show you something. You don't know what's going on because you can't see, you know what I mean? So like I say, I still don't think she was very good because I had to say pardon all the time, and she didn't tell me about the microphone. I don't really have a lot to do with them. I'd like to, because obviously there is a lot of things I'm missing out on. But if you get one that comes to your house and they're not very good you're not inclined to sort of make an effort are you? The more helpful, and they understand that you can't see properly and they help you in that way, then it's like they've encouraging you to get in touch with them again."

It is suggested that professionals who are assessing the communication needs of individual dual sensory impaired people should consider the provision of equipment prior to or in addition to training in new communication methods, such as the deafblind manual. It was the researchers’ experience that some dual sensory impaired people like Christine Bell preferred to continue making maximum use of their residual sight and hearing even when this had become quite limited. Some may therefore prefer to use aids rather than learn the deafblind manual. Individual choice needs to be maximised.

Further research is also needed to improve our understanding of the kinds of aids from which dual sensory impaired people would benefit. Given the large numbers of older people with a significant visual impairment who are potential hearing aid users, it would seem to be a good idea for manufacturers to consider the ergonomics of their designs more carefully. For example, many currently-provided hearing aids are miniaturised, and are therefore difficult for people with a visual impairment to manage, particularly those older people who may also experience a lack of sensitivity and movement in their fingers. The result is that the very people who most need amplification are likely to have the most difficulties when using the aid.

Dual sensory impaired people also require information about all the aids and services that are available, and to be able to choose those which meet their needs. Ideally, this information needs to be easily available in their local area. One way to achieve this could perhaps be by developing several "sensory impairment centres" in the county, where information, advice and aids could be made available. H.I. (Hearing Impairment) Kent, a large local voluntary organisation, have adopted just such an approach with "High Street" premises in several towns.

Consideration also needs to be given to the issue of the funding of equipment for dual sensory impaired people, some of which is very expensive. Radio loop systems cost several hundred pounds, and computerised equipment can cost several thousand pounds. At present service providers seem
reluctant to find the money to provide the aids sensory impaired people need. Philip Hammond for example had a "lot of trouble with the hospital services" when it came to providing him with hearing aids. He was aware of his entitlement as a blind person to two hearing aids; the hospital agreed to this, but they "iffed and butted" about paying £1000 to purchase the special glasses which incorporated the two aids which he needed. He was placed on a priority waiting list, which was a year long. After telephone calls and letters to the hospital failed to have any effect, Philip wrote to his MP. He was seen within a few days, and the equipment "approved and provided in eight weeks".

It is argued that dual sensory impaired people should be afforded priority in the provision of aids so that they can maximise on any residual sight and hearing they possess. It appears that some aids which are little used are almost automatically provided, whilst others, which could make a significant difference to the lives of dual sensory impaired people, are neither considered, publicised nor provided.

It is further argued that dual sensory impaired people be afforded priority in the provision of rehabilitation services. For example, an easily accessible hearing aid back-up service is required, along with the services of a hearing therapist. Currently, only two such therapists exist in Leicestershire, and in consequence, an ageist policy has been adopted, with priority being afforded to those under the age of sixty-five. Given the severe communication difficulties experienced by dual sensory impaired people, it is suggested that priority is afforded to people of all ages who have a combined vision and hearing impairment. The same could apply to other rehabilitation services provided by the Health Authority, the Centre for Deaf People and the Society for the Blind.

3. Training dual sensory impaired people in communication and coping skills

i) Communication skills

It would appear to be beneficial for dual sensory impaired people to be provided with information, advice and training on communication skills, including the specific effects of their own impairments, the importance of environmental factors, and so on. Training would need to be closely related to the individual's particular communication requirements; for example, many may only need some general advice about optimum lighting and so on, whilst a small number of people who have developed severe impairments may need to be taught new methods of communication, such as the deafblind manual. However, before any such training is offered, three factors need to be taken into account; assessment, choice and the need for support.

First, accurate assessments of the nature and severity of impairments need to be made. For example, Sarah Miles' Home Carer. was extremely concerned that she did not use her hearing aid, and would benefit even more from an up-to-date aid. She felt very strongly that if only Sarah would use such an aid, the quality of her life would be dramatically improved.

"It's just that since the time that Sarah lost her hearing till now there have been such great developments in things like aids, and new technology and such like. You can't help thinking there must be something that could help."
Subsequent to the interview, however, Sarah was referred to the ENT Department of her local hospital, where it was discovered that she had no hearing at all in her left ear, and very little in her right ear. A hearing aid would therefore be of no help to her in discriminating speech. The hearing therapist who dealt with her had been forced to use very large print to try to communicate with her, and expressed a feeling of "impotence" in being unable to help her.

Clearly, if Sarah had had regular hearing checks, the reality of her situation would have been identified earlier, and appropriate communication training, such as the deafblind manual, could have been offered.

Second, some of the older people the researcher had met in the course of her work who had been taught the deafblind manual appeared to be reluctant to use it, preferring to struggle to use whatever remaining sight and hearing they had. There may be a number of possible reasons for this. Most importantly, it has to be recognised that this is another area of choice. It appears that solutions are sometimes imposed upon dual sensory impaired people by well-meaning professionals.

Third, although people should be given the opportunity to learn this method of communication, it has to be recognised that the use of the manual depends on the availability of someone to teach it and to reinforce its use; this can be time-consuming, and adequate staff resources have to be provided.

As was noted in the section on education, some of the congenitally deaf interviewees may well have benefited from having been taught British Sign Language. As well as giving them access to another language for communication, this may have helped them to adopt a positive identity as a Deaf person and given them access to Deaf culture and the Deaf community. It is suggested therefore that opportunities are provided for individuals to learn BSL.

ii) Coping skills

Dual sensory impairment is not always "visible" to others, and some of the interviewees, particularly the older ones, appeared to deny or attempt to hide their impairments. In consequence, it is often not immediately clear what the particular communication requirements of a dual sensory impaired person might be.

However, some interviewees had developed various strategies to cope with problems they faced in communicating with others. One successful strategy appeared to be acknowledging their impairments and advising others how best to communicate with them. This very assertive approach seemed to work well.

"Because they don't know I've not got anything wrong with me. They don't know I can't hear or can't see if I don't tell them they just think I'm stupid. I would rather them know than let them think I'm stupid." (Janice Masters)
"I think if you give people a chance to help, I think they're pretty good really. I think it's when you don't say that's when the problems set in." (Andrew Duncan)

"I just have to say to them I'm deaf would you mind speaking clearly and loud and fairly slow." (Molly Richardson)

The effect of using this strategy is that others are made aware of the person's communication needs, and can respond appropriately. Those that had adopted this approach seemed to feel that people generally responded in a positive, understanding way. It may be that dual sensory people could be enabled to learn from one another about how to cope with communication difficulties, and that other effective coping strategies could be explicitly taught. These may help people to deal with the stress they encounter as a dual sensory impaired person.

4. Communication skills and advice for carers

The people in regular contact with dual sensory impaired people, such as friends and family members, could also benefit from information and advice about effective communication techniques. Some dual sensory impaired people may need only minor changes in other's behaviour to meet their communication needs.

For example, family members could be advised about the benefits of holding a conversation in a quiet room, ensuring good lighting and positioning themselves appropriately, getting the person's attention before starting to talk, directly facing the person, talking slightly slower, and using normal, rather than exaggerated facial and hand gestures. In the case of older people, it may be helpful to allow the dual sensory impaired person more time to receive messages and to respond.

For those dual sensory impaired people who learn the deafblind manual, it would be vitally important to ensure that their carers can also communicate using this medium.

5. Public education about dual sensory impairment

Some of the interviewees stressed the need for greater public awareness of the communication requirements of dual sensory impaired people, and a better understanding of the effects of a dual sensory impairment.

"They could find way of getting people educated more to speak a bit slower. A bit clearer so a deaf person can lip-read just like.... if I turn my head away and you said something to me I wouldn't be sure. While I can see you I can grasp what you're saying." (Alan Woodger)

"Ask people to repeat things and talk to me and not my back." (Andrew Duncan)

"I think that there has got to be a lot more awareness of people that have got a handicap to make sure that they get through to you. I don't know what product they're
selling or what service they're selling at a bank or whatever. Definitely because I mean these grilles at a post office or bank if I'm with somebody they probably look at my mother and I wouldn't hear what they are saying at all, and I'd say sorry can you speak up. I think so many people naturally assume that if you can't see or hear too well you're some sort of idiot or something. If you are with another person they always tend to address the other person and not you and that's always bugged me." (Andrew Duncan)

This would suggest the need for information, advice and training to be provided on communication methods and skills.

6. Environmental improvements

Environmental improvements required by single sensory impaired people would often also benefit dual sensory impaired people. For example, clear, large print signs, loop systems, better lighting, the use of colour contrast, and the provision of information in appropriate formats such as large print or Braille are all needed by both groups. However, for dual sensory impaired people, it is important to recognise their very specific needs. If these are not taken into account, they may not gain full benefit from these improvements. As with aids and equipment, relatively minor changes may be all that is required. This is well illustrated by Janice Master's experience.

She had recently gone to the theatre, and having just heard of the existence of loop systems, was keen to try one out. Unfortunately, no one had informed her that she needed to turn her hearing aid to the "T" position, and she was therefore unable to hear what was going on. Janice felt that loop systems needed to be better publicised, and that dual sensory impaired people should be better informed about their existence. Current information and signs about loop systems do not take into account the needs of people who have a visual impairment.

7. The need for "human resources" for access to the community

Some of the dual sensory impaired people interviewed relied heavily on their carers to assist them with communicating with others. This can have negative effects including reducing the independence and autonomy of the disabled person, distorting their relationship with their carer, and causing a heavy burden on the other person. Some required a "human resource" to enable them to gain access to services in the community and to reduce their isolation. Several initiatives are suggested to meet this need.

For example, one way would be to develop a Guide Communicator service for dual sensory impaired people, as suggested in recent reports (Deafblind Services Liaison Group, 1988; Department of Health, 1989). Guide Communicators are employed as personal assistants for dual sensory impaired people. They may be employed for varying lengths of time to suit individual need, and would undertake a range of duties. These might include enabling an individual to join a local group, assisting with correspondence, escorting a person shopping, and so on. This service can involve fully trained paid employees such as the scheme currently in existence in Norwich.
A second way for dual sensory impaired people to obtain a personal assistant could be through the recently developed Leicestershire Independent Living Scheme. This would have the advantage of offering them more choice and control of the person employed. The Government currently does not allow Local Authorities to make direct payments to disabled people so that they can purchase for themselves the help which they require.

A third answer would be for the government to provide dual sensory impaired people with a "communication allowance" which would enable them to employ their own personal assistants. This would afford people maximum choice, control and independence.

In addition, all service providers would need to guarantee access for dual sensory impaired people by the provision of interpreters or human aids as required on an individual basis. Consideration may need to be given to training interpreters who work with Deaf people to work with dual sensory impaired people.

Mobility and transport

Although some of the younger interviewees travelled alone into a local town or city, approximately half of the adult interviewees were unable to go out unless they were accompanied by another person, and none of them went out alone in the dark. This was because some eye conditions lead to a form of night blindness. For example, Henry Cramer's father always accompanied him to the bus stop in the evening or in the winter when it was dark. Getting about was clearly a stressful activity for all of the adult interviewees, particularly in unfamiliar areas.

Andrew Duncan found his way around the family small-holding, but always went to the local village or town with his mother or sister.

"I can't see away from here if I find I'm somewhere strange. I'm okay here because I know my way around so well. But if you put me in a town or somewhere strange, to get on quickly I have to hold onto somebody's arm, otherwise I'd go really slowly because I'd think I was going to walk into something, a lamp-post or people or whatever."

Christine Bell would have liked to have been able to go to the local park with her dog, but was unable to get there. She also missed going to church. Her life was restricted because she needed another person to accompany her.

"I've got to have someone with me, I need someone with me."

Ram Pancholi required assistance to get around inside the house, particularly up and down the stairs. His wife always accompanied him if he went anywhere beyond the house, but this rarely occurred.

The situation was worse for the older dual sensory impaired people. All of them experienced mobility difficulties, and the majority very rarely went out of the house alone. Like Ram, some of these
older people also experienced difficulties getting around their own homes. This was particularly the case for those who were frail, or had chronic long term illnesses or physical disabilities.

"I can't go out, of course. I never go out. I think that's mostly due to old age. I can't walk, you see. All the same the sight and the hearing doesn't help, you see. I won't dare go out by myself... I can't go to the length of the garden now and I can't get around the room without a stick. You can't have a stick in your hand all the time, so I pull myself around by the furniture." (Molly Richardson, who lived alone)

A third of the older people interviewed had experienced a fall or falls in the past twelve months, which for some had resulted in hospitalisation. Previous studies have suggested that impaired vision and hearing are important risk factors for lack of balance, falls and injuries (e.g. Gerson, Jarjoura and McCord, 1989). As a consequence of these falls, they had experienced a loss of confidence in their abilities. David O'Brien had been quite active but had recently experienced several falls. Subsequently, he spent much of his time in bed or in his dressing gown sitting in the lounge. He no longer went out of the house.

"He spent three weeks in bed before Christmas, because he had two falls. He didn't hurt himself but it frightened him." (David O'Brien's wife).

Carol McPherson had had a Piper Lifeline provided by Leicester City Council for which she paid £1.00 a week. Carol felt it was an excellent service as she lived alone and sometimes lost her balance and fell. The lifeline gave her confidence.

The traditional way of addressing the mobility needs of visually disabled people is by the provision of mobility aids and appropriate training in their use. All of the dual sensory impaired interviewees who were registered as blind or partially sighted had automatically been given a white cane, or in some cases a white cane with red bands on it, which indicates that they have an additional hearing impairment. It was very disconcerting to find that in at least one case, absolutely no advice or guidance in the use of the cane appeared to have been given.

"I phoned up the Society for the Blind and somebody just came and gave me a white stick and I stood at the kerb and I thought cars would stop if they saw a person with a white cane, but they didn't. A man brought it. They didn't say what you had to do with it or anything. They just gave it to me and that was that, and I thought well, this is no good to me." (Janice Masters).

The majority, however, did not attempt to use their cane at all, and gave varying reasons for this, including:-

"Yes I can see good enough without a stick. I can't see very good but I can see good enough to not use one." (Paul Ward)
"I feel the same way about white sticks. I think it makes people vulnerable as a mugging point." (Philip Hammond)

"When you are young you are conscious about things aren't you? People looking at you. With a dog they want to come and stroke it and if a man comes and strokes it he might just start chatting you up, you never know. Perhaps, if we were old it wouldn't matter what we used as long as it got us about." (Janice Masters)

These statements suggest that the fear of attack and the perceived stigma of the cane can result in a reluctance to use it.

Only a very small number of the interviewees had a red and white striped cane, and Hazel Simpson felt that more public awareness was needed of the meaning of the red and white symbols:

"I've got this stick with the red on. I took it to work and nobody in my department knew what it was, so my husband took it to work in his office and nobody knew. He himself didn't know, been a driver all these years. I think they ought to advertise it on television. Times I've said that. Then I took it north to his cousins. They didn't know. Nobody knows."

It would be helpful to educate the public on this issue.

Only three of the interviewees had received mobility training; the majority had received none. Christine Bell, who lived alone, had recently had some training in the use of a long cane; she walked around the block to exercise her dog.

"I don't go far on my own. I do go round this block with my dog, but I'm afraid I'm a little on edge all the time in case there is something I won't see and bump into it. One or two leave their gates open when they come in and out with their cars.... I fell over a little girl the other week, she was lying on the floor."

Bill Broadhurst's wife encouraged him to go out "to retain some independence". He had had mobility lessons eight years ago, but had only recently, and somewhat reluctantly, begun to use a cane.

These interviewees described finding it very difficult to judge when it was safe to cross roads.

"I've got to try and hear the car coming. I can't always hear. If it gets near enough I'll see it but they're pretty good. You've got to have the sense to hold your stick out, cane or walking stick, and give them a chance. They usually stop." (Bernard Oakley)

Janice Masters stated that she was "sort of guessing" when it came to crossing roads and she had been knocked down a couple of times.
"It's like I don't know the difference between the grass and the pavement. I know where the lamp posts are but I'm pretty desperate in case I bump into them. It's terrible .... I'm very nervous anyway when I go outside."

A single mother, she often relied on her children, aged four and seven to guide her.

"The boys are great. They hold onto my arm and guide me wherever I'm going. It's not easy to guide somebody who cannot see at all. That is one of my big problems."

Currently, Rehabilitation Officers for the Blind receive little training on working with dual sensory impaired people, and therefore lack the knowledge and skills to undertake this specialist area of work. It is suggested that in order to enable dual sensory impaired people to have access to mobility training the current courses for Rehabilitation Officers need to be improved and "top up" training provided.

Alternatively, it may be that mobility training is not the complete answer for many dual sensory impaired people. In spite of such training, all of the interviewees continued to find going out difficult and stressful. To enable them to have the mobility they require may mean looking afresh at the disabling effects of the environment, the need for adequate income for dual sensory impaired people and the use of a personal assistant as mentioned earlier.

Interviewees felt that various improvements were needed to the environment to enable them to get about more easily. These included:-

- Constructing islands in the middle of the roads (this meant it was only necessary to look in one direction instead of two)
- Providing more pelican crossing points
- Increasing the length of time allowed for pedestrians at crossing points
- Building footbridges and underpasses
- Ensuring adequate street lighting
- Reducing uneven surfaces (using tarmac instead of slabs)
- Marking step edges in a contrasting colour

None of these ideas is particularly radical, and would improve safety in the urban environment for many other groups of people.

A small number of the interviewees had bus passes and used local buses fairly regularly, but they felt that various improvements were needed including:-

- Providing a sloping deck entrance
- Placing the number of the bus at face height at the side of the entrance
- Highlighting the stop button with a yellow circle
• Marking the edges of steps with bright colours and decreasing the numbers of steps from three to two
• Painting the bus stops and buses in bright colours
• Erecting thick plastic handles
• Providing a skeleton Sunday service
• Ensuring that the buses ran on time

Again, these are relatively small changes which would be of benefit to many people.

Only one or two of the interviewees appeared to make infrequent journeys by public transport beyond their local town or city. Again, small changes could make this activity a little less problematic for dual sensory impaired people. For example, Janice Masters had recently travelled by train for the first time alone. She had pressed what she thought was the button for the toilet and had stopped the train. Given a clear large print sign this may not have happened.

Molly Richardson used the Dial-a-Ride scheme to go out shopping occasionally with her daughter. She appeared to really enjoy these trips which were the only times when she left the house. She felt the service was extremely good:

"I mean it's very, very convenient and it's friendly and it's nice. Otherwise I haven't been getting out."

The development of more transport schemes for disabled people such as Dial-a-Ride would appear to be beneficial. Many of the interviewees were unaware of this scheme, which suggests the need for improved publicising.

Some of the interviewees used taxis when they went out on their own as they found using public transport such as buses difficult and stressful. John Brown had become dual sensory impaired in recent years and was clearly frustrated by the restrictions he now experienced. He was no longer able to drive, and so the car had been sold. He was unable to go out alone, because of balance problems and difficulties crossing roads, and he had to rely on his wife to accompany him everywhere. He and his wife relied on friends or taxis to provide transport for their infrequent trips out.

Donna Philips used a taxi when she went shopping at the supermarket.

"I don't really want to go on the bus. Sometimes I go in taxis. They know me, see. Then they help me put shopping trolley in the back. They open the door for me to go in the car."

Paul Ward also preferred to go by taxi, as he was never confident about which was the right bus to catch, being unable to see the numbers.
Several of the people interviewed used taxis to enable them to get to the local shops, rather than attempting to walk there. Clearly, taxis are costly but it is argued that they are very important for maintaining the independence of dual sensory impaired people. Clearly an adequate income is required to enable them to take advantage of this means of travel.

Generally, most of the interviewees relied on their carers or family and friends to accompany them to any events or activities. This study appears to confirm the findings of the Inter Regional Committee (1971). They reported that:-

"Even a small hearing loss (perhaps even in one ear only) is said to have a severe effect on orientation and sound alignment. Background noises of hearing aids may confuse and lack of sound clues disorientate. The conclusion reached was that blind people whose hearing is seriously impaired are rarely mobile alone and that even with a guide they are inclined to be nervous through sheer lack of confidence. Without a guide they become disinclined to go out at all."

The use of a personal assistant as mentioned in the previous section, would clearly not only help meet people's communication needs, but also assist them in getting about safely. Not least, it would enable dual sensory impaired people to be independent of their family members who currently often act as guides for them.

**Personal care and household activities**

1. Personal Care

The majority of the adults interviewed in this study did not need any assistance with personal care tasks. Two exceptions to this were Ram Pancholi, whose wife washed and dressed her husband, and May Francis, who had multiple sclerosis and required regular help throughout the day. Community Nurses came every day during the week to help her get up and into a chair, and to assist with toileting; and Home Carers and an assistant paid for by the Independent Living Fund undertook household tasks and prepared meals for her. May's husband undertook all these tasks at the weekend. May expressed satisfaction with these arrangements and did not feel that she required any additional or alternative help.

The older interviewees needs for assistance with personal care tasks varied widely. Some, particularly those who were frail and/or had other impairments, needed a great deal of help, whilst others needed very little. Assistance was generally given by members of the family. David O'Brien, for example, although he appeared to be physically able to look after himself, had become depressed and withdrawn following the deterioration in his vision, and his wife helped him to wash, dress and to bath himself.

Assistance with bathing was a need expressed by three of the older dual sensory impaired people. There appeared to be some confusion about which agency could help with this task, and two of the interviewees had recently been advised that no such help could be offered. Molly Richardson's
daughter was very concerned that her mother was “smelly”, and was exploring the possibility of paying for someone to come and give her a bath once a week. Negotiations were taking place at this time between the Social Services Department and the Health Authority on the issue of which agency was responsible for bathing and whether it should be regarded as a "health" or a "social" need.

Formal support from service providers was provided in the form of Home Carers for some of the older interviewees who lived alone. Alison Taylor, for example, who was aged ninety-two years, had an intensive package of support, which along with a significant amount of help from her neighbour, enabled her to continue living in her own home. (It was the view of some professionals involved in her care that she would be better off moving into a residential home). This support included Home Carers three times a day, who helped her to get up in the morning and to go to bed at night, prepared meals, undertook her housework and so on; and a nurse who visited her twice a week to give her a shower and to treat her feet.

2. Household activities and shopping

Traditionally, in response to their perception of people's needs in this area, service providers have supplied aids and Daily Living Skills training, and support in the form of a Home Care service. In this study, the adults generally appeared to have been offered the former, and the older people the latter. It appeared that standard solutions were being offered and that little account was being taken of individual differences and the concept of choice.

The provision of aids to daily living and training, for example, was clearly linked to registration as a blind or partially sighted person. Three of the interviewees who were born hearing impaired and who were experiencing a gradual deterioration in their vision were reluctant to accept help from a "blindness" agency. The impression gained during the conversation with them was that they were having difficulty accepting their visual impairment, and were fearful of impending blindness.

The use of aids by those who had received them from the Society for the Blind varied widely. Some never or very rarely used them, preferring to seek assistance from others. Jenny Broadhurst, Bill's carer, did not feel that any of the aids she had seen were useful to them:-

"I mean, there was a Social Worker from Huddersfield. Very good at coming round. I think he was on commission for what he sold. Packs of cards, dominoes, thing for slicing bread, no use nor ornament to us. We used to take it back. We buy sliced bread."

For other interviewees, however, the aids appeared to be extremely useful pieces of equipment. Christine Bell, for example, who lived alone, had been provided with a variety of aids which enabled her to manage daily tasks on her own. She had a writing frame which enabled her to write out a shopping list for the Home Carer, a guide to help her sign her pension book, tactile markings on kitchen items such as the washing machine and cooker to assist her in their use, a clock with large print figures so that she could tell the time, and an Eezee Reader which enabled her to read her correspondence and books.
Carol McPherson had obtained "various gadgets" from the Society for the Blind, and was highly delighted with her tactile watch; previously she had been unable to tell the time. During the course of the project the researcher came into contact with several older dual sensory impaired people who had experienced a loss of sensitivity in their fingers such that they had been unable to feel the tactile watches which are currently available. Understandably, they were extremely concerned by their inability to tell the time, which for some compounded feelings of disorientation.

A small number of the interviewees appeared to have benefited from the services of a Rehabilitation Worker for the Blind. Janice Masters had recently been on a "daily living skills course" at the Society for the Blind, and was full of praise for the help she had received. She had learnt new cooking skills, bought equipment for her kitchen, learnt how to use colour contrast effectively, and purchased a large print cooking book which enabled her to follow recipes for the first time.

"I had a lot more problems before I went on that course, but I don't have so much now because I've had a lot of help.... I used to have a lot of problems in the kitchen.....Ever since I have been on that course it's really opened it up for me. I've started joining other things as well.... I think I've got a lot more confidence now."

She was now looking forward to attending a do-it-yourself course:

"I'm looking forward to that because with me being on my own there are quite a lot of things that I'd like to do in the way of drilling and changing plugs and things like that. I'd rather do it on my own than ask my Dad."

It was the minority who appeared to have had such intensive help, and only one of the men had had any assistance in this area.

In fact, the experience of being a dual sensory impaired man or a dual sensory impaired woman was very different in respect of household activities. Generally, the men were dependent upon their female carers to carry out these tasks. The women saw these tasks as their responsibility and undertook them themselves, usually with assistance from others in the family. Some of the adult women had worked out individual strategies to overcome potential difficulties when shopping. Hazel Simpson, for example, now shopped once a week, assisted by her husband, and Donna Phillips used a taxi to get to the shops, and would only visit those places where she was well known and understood.

In almost all cases, support in these areas came from the immediate family. There was very little formal support for the adults interviewed. Apart from May Francis, Christine Bell was the only adult interviewee who had any assistance from service providers. A Home Carer visited her twice a week to accompany her shopping and to undertake some other household tasks.

The gender differences in undertaking tasks in the home were similar for the older people, but their situations were rather more heterogeneous, and they were generally more dependent on others.
for assistance in this area. Many, who lived within a family unit, relied heavily on them for assistance; others, living alone, were supported by a combination of help from statutory agencies and family members or neighbours; and a third group who lived alone sought occasional support from neighbours.

None of the older dual sensory impaired people who lived with members of their family undertook any household tasks such as cooking or cleaning. In general, the carers took responsibility for household chores; none of them received any help from Social Services. Bernard Oakley, however, would occasionally heat up a meal which his sister had prepared for him in a microwave. Bill Broadhurst felt that it would be very dangerous for him to attempt to cook. He was a "safety risk" in the kitchen, and had several times set fire to things. He did, however, go to the local shops for his wife, but was now nervous about walking down the street, and only visited those shops where he was well known and the staff were willing to help him.

Four of the older interviewees who lived alone had help from a Home Carer and the Meals on Wheels service. The majority would have preferred their own cooking; only one liked the food which was delivered. The help they received from the Home Care service varied in frequency from once a week to three times a day, seven days a week. Key tasks undertaken by the Home Carers included shopping, collecting pensions, cleaning, and food preparation. Generally, these tasks were concerned with basic, functional survival, and service users did not appear to have much control over the input they received. Nevertheless, they were grateful for the help they received, and expressed satisfaction with the service. For example, John Brown had had the same Home Carer for six years, and was full of praise for her.

"I wouldn't be without her for all the tea in China."

She came every day to prepare his meals, clean the house, do his shopping, deal with his correspondence, and so on. At the weekend, a different Home Carer visited him to prepare his meals. Recently, the service he received had been reduced due to financial constraints. Bill appeared resigned to this situation, but would have preferred the Home Carer to have been able to stay longer as before:-

"I should like her to stop a little bit longer as she used to. I suppose they've all got this four pounds an hour stint on their minds, and a lot of the girls have been knocked down a lot. And they're all lovely girls."

Some of the older women who lived alone tried very hard to maintain a sense of control over their daily lives. Sarah Miles, for example, managed all her own personal care, including washing, cleaning, and cooking. She had reluctantly agreed to have a Home Carer once a week to collect her pension and to do her shopping. Her home carer stated:

"She gets on pretty well really. Apart from shopping she is very independent. She won't let anyone do anything else."
The two older women who lived alone, and who did not receive any formal support, had had to seek help from neighbours with shopping. Edna Gash had arrangements with various neighbours to collect her pension, loaf of bread, tinned food, and other basic foodstuffs.

"I've got my neighbours well trained."

Carol McPherson only went out of the house once a week to give her neighbour a shopping list. Her neighbour's son bought her provisions every Saturday. She had tried unsuccessfully to get assistance from the Home Care Service. She was having difficulties using the cooker and she needed better lighting in her kitchen.

"I have been a little worried lately because I don't put the switches on right. I put them on the low when they should be on the high, on the high when they should be on the low, consequently I get many burnt offerings. A fortnight ago I had a whole dinner absolutely black. I didn't know what was going on until I went out there and that place was full of smoke from the dinner.... I have a large torch over there which I use. You need your hands. You don't need to hold a torch. If I could switch on a light it would be very helpful."

Two of the interviewees who lived alone also benefited from assistance from other sources. Molly Richardson, for example, had a volunteer visitor from Age Concern come to see her every week. He brought her any shopping she needed and she really enjoyed his company. Carol McPherson had "two little school girls" come to see her on a Monday evening who would undertake small tasks, such as going shopping for her.

Despite arranging assistance from others for basic tasks, some of the older interviewees who lived alone identified unmet needs, such as help with small jobs like washing curtains, window cleaning, gardening and so on. They had difficulty finding people who could undertake such tasks, which were not regarded as a priority by service providers.

The reality for both adults and older people was that tasks were often done for interviewees by both informal and formal carers rather than with them. This was clearly necessary or preferred by some dual sensory impaired people, particularly some of the older people but others were being denied the opportunity to engage in an everyday activity such as shopping, and choice and control were being taken away from them. Such practice of "being done to" rather than "with" can create helplessness, and reinforce dependency. This has become known as learned helplessness (Grabber and Seligman, 1980)

It is argued that service providers need to recognise the danger of disempowering people, and develop a flexible approach which aims to maximise dual sensory impaired people's control of their own lives. Clearly a further benefit of a personal assistant scheme such as a Guide Communicator service would be the independence it gives dual sensory impaired people in this area.
Small but significant environmental changes are also required by dual sensory impaired people to improve their access to facilities in the community, such as shops. Several of the interviewees raised the issue of poorly printed prices on products in the shops. Hazel Simpson deliberately shopped at her local Iceland store because she found the prices easy to read. Janiee Masters was impressed by Marks & Spencer’s "black thick numbers".

"Whereas you go into places like Poundstretcher, it's yellow and then it's grey and sometimes I can't even see what it says with my magnifying glass. So I think they must use the cheapest prices they can find. Sometimes I feel like complaining to them. I feel like saying I can't even see this. But I know I'm not the only one that has trouble in reading what the prices say, because I've had no end of people asking me."

It would appear that awareness needs to be raised about access issues for dual sensory impaired people, such as ensuring adequate lighting, providing clear signs and labels, minimising background noise and so on. Schemes such as that recently put into operation by a large supermarket chain, which provides shop assistants to accompany disabled people, could be one answer.

**Employment**

Previous research has shown that disabled people are subjected to discriminatory attitudes and practice in the field of employment, which results in many of them being unemployed and under-employed.

"The data show that disabled people are more likely to be out of work than the rest of the community, they are out of work longer than other unemployed workers, and when they do find it, it is usually low paid, low status work with poor working conditions."

(Barnes, 1991)

The adults interviewed in this study clearly experienced disadvantage and a lack of opportunities in employment. Only three, all males, had a job; most appeared resigned to being unemployed.

For those interviewees who were in work, things were not easy. Henry Cramer worked in a knitting factory and felt that he was very lucky to have a full time job. Philip Hammond worked for the Social Services Department. Over the years, Philip had had many battles to get his needs recognised and met by the Social Services Department and Manpower Services.

"The more you prove you are able to cope in your work, the more independent you become, the more difficult it is to tell professionals that you have problems. The people that should understand don't know a darned thing about it. They don't want to know."

To enable him to undertake his job, he had recently been provided with an Opal computer system by MSC, which "read" all his correspondence to him. He was entitled to a reader for two hours a week and had access to a driver. However, to ensure that he completed his work satisfactorily, he spent many extra hours working in his own time at home, as did his wife, who read for him.
Andrew Duncan had spent most of his working life assisting his father with the family riding school. His father had died a couple of years ago, and he had attempted to carry on working with the horses. Unfortunately, Andrew's vision and hearing had deteriorated and he was finding it very difficult to manage. He earned just enough to pay the bills.

"I've been in horses since I was sixteen and I'm forty-four now. I desperately want to carry on doing a bit although the handicaps are stopping me from doing it. So I sort of stubbornly try and stick to.... It's hard."

He recognised that he needed to change direction but was unaware of what help was available. He felt that there should be a local resource, rather like the RNIB's Rehabilitation Centre at Torquay, where dual sensory impaired people could learn new skills such as Braille.

Other people, like Hazel Simpson, for example, felt that they had failed to reach their potential at work because of discrimination on the grounds of their disability. Hazel had initially wanted to take up a career as a State Registered Nurse but was rejected because of her deafness.

"They gave me a test and said that there is nothing wrong with my brain. The tutor told me this afterwards. They said my intelligence was above, well above, it's because I didn't hear. I've only got one ear. If I had got two ears then I would be bright. So I had to give up nursing, you see, and this is the way I got my nursery nursing"

She subsequently became a nursery nurse and was in charge of a nursery at a local hospital for twelve years. A year before she was due to retire, her vision deteriorated and the hospital decided to demote her. The Employment Service and the union she belonged to were prepared to help her fight her case with her employers, the local Health Authority, but she decided against taking action.

"I've had to fight it all my life to get where I am with my handicap. I could have a chip on my shoulder if I wanted to but I rose above it. I'm not going to start now."

She was understandably very bitter about her experience.

The loss of a job on the grounds of disability was common amongst the interviewees. Donna Philips and Christine Bell had both stopped work as a result of their deteriorating vision.

"I had to give it up because I couldn't read the writing. I couldn't do the job properly. I couldn't see what to do. But I loved the packing."

As a consequence, some had adopted a strategy of trying to hide their disabilities. For many, this had proved successful for a while, enabling them to continue working until their disabilities were "discovered".
"I didn't sort of say I'm partially deaf and partially sighted, I sort of hid it most of the time." (Janice Masters)

"Up until eleven years ago I was working as normal. I was just doing the same as anybody else was doing. But it was a bit harder for me 'cos I was having to struggle through 'cos I didn't see good enough. But I could still do it.... Labouring work, you don't really need eyesight. I can chuck stuff in a mixer without even looking, I can. Once there's a plank and ladder I'm good at balancing and going up ladders and going around scaffold. That never bothered me because it wasn't close vision to look at. I was all right." (Paul Ward)

"I knew the feel of it and a lot of things I could virtually do with my eyes shut sort of thing, so I could get by and make it look good." (Alan Woodger, engineering tradesman).

Paul and Alan had both lost their jobs. Paul Ward said that he had had to stop work because new safety regulations were implemented. He was advised to register as a blind person. This was some years ago, and although he had been unemployed since that time, he had been using his skills to renovate his home. Alan Woodger had worked for eleven years in the engineering trade. He was attending a Skills Centre when his visual difficulties were noticed. Once his severe vision and hearing impairment were recognised, he was told that he was "unfit for work" and not to expect to work again.

"They told me now that I'll never work now with my disability. 'Have to put you on a disabled pension until you're sixty-five and then you get the old age pension.' That's what they turned round and said to me.... When I came home, for a few minutes I sat here and thought to myself you know.... I wasn't crying but I filled with the shock of it. I filled with the shock of it.... So I had come from work, to the training, to the dole then - woof"

He appeared to have been offered no training or assistance by the local Employment Services. They had mentioned to him the RNIB Rehabilitation Centre at Torquay, but:-

"When they examined me up the medical centre, up Brown Street, they said 'Well what's the point of sending him there, costing the authorities about a hundred odd pounds a week, to learn something like basket making or stuff like that.' Which all right, if somebody gave me a basket to make, I'd learn it. I would be upset and I'd think, 'Oh, is this all I'm fit for, with twenty years work behind me.' So what they done was with me being disabled, I'd gone over the borderline for "unfit for work". If I'd have had, say, a bit better eye sight and a bit better hearing and not have this problem, then quite possibly they would have said, oh we'll try and get him a job."
He had felt an "outcast", "not wanted" and "on the scrap heap". He was now resigned to being unemployed. He claimed benefits, and like Paul, continued to use his skills, doing "jobs on the side" in order to pay his bills, buy essential clothes, and so on.

Several of the interviewees expressed the need for training and employment opportunities. Alan Woodger, for example, felt that the Government should ensure that firms employed a certain number of disabled people. He also felt that he should be given a "test", a chance to prove that he could do the job. Janice Masters also felt that her opportunities for work were restricted and that she should be given "a chance".

"I could do a better job. I would like one day to work in a nursing home but because I can't see properly and I can't hear properly I can't really see them taking me on, and yet I've had eight years experience. But they'd rather have somebody whose got better hearing, which I can understand, but I just know that I could do a good job. And I really think that you should be put on a trial, given a chance. I don't think there should be any such thing as cheap labour 'Just because you're disabled we'll give you £40.00 per week'.'"

It is suggested that professionals in the employment field would benefit from improved understanding of dual sensory impairment. Information and training could be provided to address this issue. A positive step has recently been taken by the creation of a multi-agency Working Party, which aims to highlight the employment needs of dual sensory impaired people; they have recently produced a basic information booklet on this subject (Vocational Opportunities for Deafblind People Working Party, 1993).

Many of the people interviewed in this study were subjected to negative attitudes from professionals working in this field. The researcher was made aware of these attitudes herself when in contact with the local employment advisors for disabled people to invite them to attend the local conference on dual sensory impairment. None of them came, and one said

"Oh come on, let's be realistic. There's nothing we can do for them".

This study would suggest that a more positive approach is needed from professionals, which would focus on and recognise dual sensory impaired peoples' abilities.

It is further argued that some of the people interviewed could have been enabled to carry on working, perhaps in a different capacity, if advice and assistance had been made available early enough, both for them and for the employer. Assistance needs to be given to employers to encourage them to retain people who become dual sensory impaired. Aids and equipment and, in some cases, interpreters or "communication assistants" may need to be provided to meet people's communication needs at work. The recent government scheme 'Access to Work' is to be welcomed in this context; this will enable dual sensory impaired people to get money to pay for communication and other types of personal support.
There is also a strong argument for anti-discrimination legislation to make discrimination against disabled people illegal in the employment field, similar to that which already exists on the grounds of race and gender.

**Finances**

Several studies have highlighted the low incomes of disabled people (see, for example, Martin and White, 1988). It was not possible to obtain detailed information about the financial circumstances of the people interviewed and of the benefits they were claiming. Nevertheless, some general observations can be made.

The majority of the adults were in receipt of state benefits and appeared to be resigned to their financial situation. A minority expressed strong views that they did not receive an adequate income. The interviewees were often unsure of which benefits they were claiming, and did not seem to be well informed of all the benefits to which they were entitled. For example, several of the interviewees were not aware of their possible entitlement to the Disability Living Allowance; and some seemed to have been awarded a lower rate than they would appear to have been entitled to, given the severity of their hearing impairment. Only three of the older dual sensory impaired people appeared to be in receipt of the Attendance Allowance.

The interviewees who had obtained the Disability Living Allowance commented on what a big difference this benefit had made to their lives:

"I get so much money each month and that helps because I am able to get things. There would have been no way on earth I could have done that without the Disability Living Allowance. I got a new cooker. It's not just a new cooker, it's a modern new cooker. But the thing is the reason why I got a new one was because I didn't know what I was doing with my old one. I had to guess what the oven was on and I couldn't see the numbers... It was just a guessing game all the time." (Janice Masters).

Some of the items needed to enable her "to see better", such as special lighting, were expensive. She was able to buy some of these with the Disability Living Allowance.

These findings would suggest the need for service providers to ensure that dual sensory impaired people receive information, advice and assistance in obtaining the benefits to which they are currently entitled.

Alan Woodger undertook "cash in hand" jobs to supplement his benefits:

"...because sometimes I do things to keep myself occupied, that you should not do under their rules. It comes to it again, they're discriminating against you. You're doing it to survive, to keep the bills down and they're having you because they say you're supposed to manage on the money they give you."
Several of the interviewees mentioned the additional costs they incurred as a result of being disabled, such as paying for taxis, extra heating costs, and having to pay people to do small jobs for them. Andrew Duncan felt sure that better hearing aids than those provided by the National Health Service existed, but he could not afford to pay for them.

Clearly, dual sensory impaired people need an adequate income which recognises the additional costs which they experience.

Social and leisure activities

Several of the adult interviewees appeared to have very little contact with others beyond their close family and friends. Susan Howard, for example, appeared to spend almost all of her time at home with her mother, with very little to occupy her. She had no friends, but occasionally saw her sister who lived in a nearby town. Her mother had encouraged her to go to the local Deaf Club in Leicester, but she had not enjoyed it because of the difficulties she experienced in communicating with the other Deaf people. Ram Pancholi sat on the sofa all day at home. Occasionally, his wife took him to Sainsburys or to a relative's home, but after about half an hour he wanted to go home.

"He says that nobody talks to him and she is saying that he doesn't have any contact."
(Interpreter for Ram Pancholi)

Ram had very much withdrawn from life around him. He no longer attended family events such as weddings, and had no wish to go out to any local events or activities. He felt he would be better off dead. May Francis, who had multiple sclerosis, watched the television all day.

"Well, I just lay back and let the world pass over. I have no choice."

Some of the interviewees were clearly frustrated by their lack of contact with others. They talked about the limited opportunities they had to meet people of the opposite sex. Hazel Simpson wanted to be able to join in community activities and classes. She found life a "bit lonely" and wanted to meet more people.

"I mean, I'm sick of the four walls."

All of the older interviewees had even more limited contact with other people beyond their immediate carers, family, and friends. Edna Gash felt that old age had led to her losing some of her friends.

"But as I say, when you get to my age your friends drift away, or else they're blind and lame or have a stroke and things like that. Your friends dwindle off."

A significant number, like Carol McPherson, appeared to lead lives that were very much confined to their home and devoid of stimulating activity. Carol lived alone; she was unable to watch television, hear the radio or read. She never went out, apart from delivering a shopping list to her neighbour on
a Friday, partly because of her difficulty in socialising with others due to her sight and hearing impairments, but also due to embarrassment about her "water trouble". A friend visited her once a week. She preferred the summer time, when she could get into the garden, and people in the street would wave to her.

"The winter time is long and dreary, but on the whole I'm quite content."

In comparison with the adults in this study, some of the older people seemed resigned to their isolation and lack of stimulation, perhaps feeling that this was an inevitable consequence of the ageing process. However, it is argued that older dual sensory impaired people should not be denied the opportunity to engage in stimulating activities. Bernard Oakley, for example, was able to use his Talking Book machine, and clearly derived a lot of pleasure from listening to talking books and talking newspapers. Molly Richardson had a weekly visitor, a befriender from Age Concern. She very much valued his company. It may be that more of the interviewees could have benefited from a Talking Book machine, if consideration had been given to their communication needs; the use of volunteer visiting schemes in addition to a Guide Communicator service could also help to reduce their isolation.

Traditionally, specialist agencies for blind and Deaf people have responded to the needs for leisure and social stimulation of these single sensory disabled people by providing activities and social groups. Their success in meeting the social and leisure needs of dual sensory impaired people was at best, limited, and in some cases, they clearly had failed completely.

A small number of the interviewees attended such groups, either for visually impaired people at the Society for the Blind, or for hearing impaired people at the Centre for Deaf People. These were generally provided for older people, but appeared to be very much appreciated by these interviewees. For John Palmer, they were the highlight of his month:

"We should all go a bit barmy without that outing. We have a real good time"

and he particularly appreciated being with other people who had the same disability.

"We understand one another."

In addition to social contact, these outings gave interviewees opportunities to seek advice, to view and occasionally purchase aids, and access to large print library books.

Unfortunately, these activities were not always accessible by dual-sensory disabled people. Hazel Simpson had approached the specialist agencies, but found that they failed to consider her needs. She had asked about activities at the Centre for Deaf People and had been told that they were for people who were profoundly deaf and used sign language.
“Someone did say that there's one at the Deaf but they didn't think that I would get on very well because unless you're profoundly deaf I wouldn't understand what's going on.”

Hazel felt that more help should be available for deaf people like herself who did not use sign language.

"I feel in a way, regards hearing, I feel more neglected on that side. I think the Blind have done more for me in a way. The Deaf people do. They've just got to get on with it."

She had managed in a class at the Society for the Blind because there were only four people in the group, but when she had tried to join a discussion group, she was unable to participate.

Hazel expressed exasperation at the treatment of dual sensory impaired people by service providers.

"They can't come down to our level, this is half of the battle. You see, they know what to do with the blind, they know what to do with the Deaf, but they don't know what to do with the two. It's a combination isn't it? I mean if I could try and find a way around it... you try and say these things."

Within these specialist social groups, dual sensory impaired people often remained isolated. Sometimes, relatively small changes could have made a significant difference to people like Bernard Oakley, who had relatively moderate impairments. He withdrew from a social group at the Society for the Blind because the speakers did not always use the microphone. Clearly, agencies need to address the communication needs of dual sensory impaired people if they are to be enabled to fully participate in activities and groups.

The situation was even more marked for dual sensory impaired people with more severe impairments. Christine Bell attended several social groups run by the Social Services Department, the Society for the Blind, and the Centre for Deaf People. She greatly enjoyed going because it was a "trip out".

"I mean, I go to the centres, that gets me out of the house. That's what I used to dread. being stuck in the house."

She expressed a great deal of satisfaction with the help that she received, but it was clear that she was not fully participating in the activities that took place at these centres and that her interaction with others there was very limited.

At the Social Services Day Centre which she attended once a week, she felt as isolated there as she was at home on her own. Christine was given nothing to do whilst there, and was very lonely.
"When I'd been going a time to two, I will admit I got a little bored because I took my knitting, but I longed for someone to come and have a chat, or me to go and have a chat with them."

She appeared to understand little of what was happening when she went to the group at the Society for the Blind

"Occasionally I pick up the odd word or two, and when I went to the Resource Centre the other week they were talking about the boat trip, and I heard him say May the eighth. I was there. I said to Susan it's on May the eighth! I don't know where we are going."

The needs of others with severe impairments to engage in social activities appeared to have been ignored by service providers, perhaps because they perceived their needs to be overwhelming. John Brown, for example, had no hearing and very limited sight, and could only communicate with others by reading large print slowly with a low vision aid. He needed one-to-one support. John was clearly very isolated and missed the social life he had once had. He expressed an interest in participating in activities at the Resource Centre, but had not been encouraged to attend.

"I don't have any invitations to social events or anything like that you know. I don't know what goes on down there really."

He was particularly keen to become involved again in bowling, which he had played frequently for over twenty years before his vision had deteriorated.

"It was a nice social atmosphere with the bowlers..... I mean, I miss all that. You've lost all that friendship. That's gone out of your life."

His main concern was about transport and his wife having to accompany him.

"But you see you can't expect my wife to keep coming. I don't want her to. She's not well herself."

Contact was subsequently made on his behalf with the Bowling Group, but they did not feel that they could cope with a visually impaired man who was also profoundly deaf, and could not provide the one-to-one support he needed. John was therefore not able to take up bowling again.

The provision of a personal assistant could have met the communication and mobility needs of both John and Christine, greatly increasing their access to social activities.

Recognising that many of the specialist agencies' services were geared towards often older single sensory impaired people, some of the adult interviewees expressed a wish to meet other adults who had a dual sensory impairment like themselves, and to attend social, educational and activity groups specifically designed to meet their needs.
"I'd like to meet people who are partially deaf and partially sighted because I've never come across them. Even in the street I don't come across them. They're either stone deaf or they've either got the one thing or the other, not got both. My friends, they're very understanding, but they don't really realise, they don't really know what it's like.... I know that there are a lot of old people who have hearing difficulties and seeing difficulties, because you do have these problems as you get older. It's not like they've had it since they were born, so there's a lot more old people. I suppose it's a disability, yes, but it's not something that they've been born with, so I'm talking about the youngsters, well from eighteen upwards I suppose." (Janice Masters)

"But there again, you'd have to go to groups that are in a similar situation to yourself. Because like we said, if you go to an ordinary group, you know they're talking rast and everything like that, you're going to feel left out, just like you feel left out on other things." (Alan Woodger)

Hazel Simpson was quite prepared to be involved in setting up a small social group of people like herself. She envisaged that they would meet in each other's houses. Such a "buddy scheme" could be developed whereby people could meet together to offer each other support, share experiences and difficulties, participate in social activities and so on. The development of this kind of group or network could also serve an empowering, advocacy function.

Opportunities for dual sensory impaired people to engage in social, leisure and educational activities should not be restricted to those provided by the specialist agencies. Hazel Simpson, who was lonely and isolated at home, wanted to attend some kind of educational and social activities; her particular interest was flower arranging. She recognised that her opportunities were greatly restricted; classes and activities for hearing and sighted people were not suitable for her.

"You see they've got classes, people keep saying why don't you join the night school. I try to keep my temper down a bit, I wouldn't be able to hear in the class."

This study has confirmed the findings of previous research (Luey et al., 1989; Nordstrom, 1984) which highlighted the social isolation of dual sensory impaired people, and their relative lack of contact with others beyond their close family and friends. As Duncan, Prickett, Finklestein, Vernon and Hollingsworth (1988) said,

"Social interaction and relationships are among the most important facets in most people's lives".

The findings suggest that dual sensory impaired people are being deprived of opportunities for social and leisure activities, and some are leading very solitary lives starved of meaningful activity and occupation.
It is argued that dual sensory impaired people should have the same rights of access to facilities provided in the community as sighted and hearing people. Service providers it is suggested need to take particular note of the requirements raised in the section on communication needs, such as the provision of loop systems and personal assistants, in order to ensure that their services are fully accessible by dual sensory impaired people.

Support from others

Most of the interviewees relied mainly on one person for help and support; in many cases this was a family member who they lived with. Other informal carers, such as other family members, friends, or neighbours generally had a minimal role. Details of this are to be found in Appendix 14.

The amount of help and support the dual sensory impaired people received from these carers varied. Ram Pancholi received a great deal of assistance from his wife with a wide variety of daily activities including washing, dressing, taking medicines, dealing with all correspondence and so on. He wanted her to be with him at all times. Susan Howard was also very dependent on her mother, and appeared to spend most of her time in her company. Molly Richardson's daughter called in to see her every day:-

"I don't know what I should do without her. She always takes me if I've got to go anywhere. Holds my hand."

Philip Hammond's wife undertook a lot of the tasks around the house which her husband had previously undertaken. Philip recognised the effect this had on his wife:-

"It puts a hell of a lot of strain on your partner. If you haven't got good partner support, I think you'd become lost."

Two of the people who lived alone relied on friends and neighbours for assistance, both for undertaking essential shopping and other household tasks. Edna Gash had herself arranged a package of support from her neighbours.

"They do their shopping on Thursdays, get me my meat on Friday. The young lady next door brings me a loaf and posts letters. The fellow next door will always get my pension. But I don't like to put on them too much. That's why I've considered this other transport. The lady next door has been in this morning. 'What time do you want taking to the hairdressers?' I'm all right really, but I don't like being beholden to my neighbours too much. But still, there you are, you have to occasionally." (Edna Gash)

Several of the interviewees, although appreciative of the help they received, expressed a feeling of reluctance in depending upon others for help.

"Well really what else can you do? I would prefer to do it myself, you know. I'm grateful but it means that you're beholden to that many people." (Edna Gash)
John Brown relied very heavily on his wife for day to day assistance. When he was asked about his satisfaction with services he replied:-

"Well - I don't have contact with them, see. Like I say, my wife is with me all the time so she does it all."

John very much appreciated her help and support. However, he did not feel that it was fair to rely on her all the time, and he expressed a desire for more independence.

Andrew Duncan lived in a converted hayloft opposite his mother's cottage. He chose to live separately in order to retain some independence, but recognised that he was increasingly reliant on his mother and sister for help when going out to the shops, dealing with correspondence and so on. When asked about the help he received from others he stated:-

"It gets a bit frustrating sometimes. That's why I like the independence of being able to do as much as I can, you know, on my own. When things get increasingly difficult, obviously you're forced to rely on people a bit more aren't you?"

Janice Masters, a single parent relied on her four- and six-year-old sons for help with any difficulties she experienced on a daily basis, such as crossing roads, but would also seek help with dealing with correspondence, going out at night, and so on from her parents, brother or friends. In reality, she would have preferred to do things for herself. One of her frustrations was that her family were not always available at the times when she needed them.

This close dependency on a family member can distort relationships, a fact acknowledged by some of the interviewees. Henry Cramer, a middle-aged man who lived with his mother, father and sister desperately wanted to have his own home.

"I wouldn't live here if I could get my own home. I'd be gone as quick as lightning."

Both John Palmer and Sarah Miles' children had suggested that they move to live with them. But neither of these older interviewees wished to give up their homes and live somewhere unfamiliar.

The need for independence and autonomy expressed by many of the interviewees has been expressed by other disabled people:-

"Given free will and the ability to exercise that free will, most adult disabled people would choose to respect and value the relationships that they enjoy with their relatives and friends, rather than compromise them by imposing demands that exceed natural bounds." (HCIL, 1990)

Having to depend on assistance from another family member to some extent places the control of their life in the hands of another, and can diminish a person's sense of their own individuality. In the
extreme case, it is possible that this relationship can be abused by the carer, who is in a very powerful position vis-à-vis a dual sensory impaired person. In some cases, carers act as an intermediary between them and the outside world, and are in a position to act as censor, effectively controlling their access to most information. For example, the researcher suspected that it was actually the carer of the interviewee who refused to participate in the study who had made the decision not to cooperate on his behalf. The consequence of this degree of possibly well-meant control can be to render the dual sensory impaired person powerless and helpless, and to take away their sense of personhood.

It is argued therefore that service provision for dual sensory impaired people needs to recognise this, and to deliver a service which considers their needs for choice, control and independence. Currently, only a minority of the dual sensory impaired people had any formal support from statutory agencies, and with one exception, that was the provision of a Home Care service which undertook certain basic functional tasks on behalf of mainly older dual sensory impaired people who lived alone. The support provided by statutory agencies should be provided on the basis of individual need, which enables dual sensory impaired people to have control of, and achieve autonomy in their lives.

Emotional needs

The interviewees' emotional reactions to their situations were very different, some seemed to have psychological needs which were not being addressed. These appeared to fall into several areas - those associated with the negative reactions of others to a dual sensory impaired person, the sense of isolation they experienced, and the sometimes quite powerful emotional reactions to deteriorating vision and/or hearing and resulting changes in their life situations.

Several people talked about people's lack of understanding and negative attitudes towards them. Christine Bell felt that other people had not always been understanding about her deafness; some had "taken the Mickey", and others had avoided contact with her. Hazel Simpson felt that more help was given to people who were profoundly rather than partially deaf, and wondered if it was better to be "totally deaf" rather than "half".

"I think it puts a strain on you when you are half of everything."

Her friends did not understand the nature of her disability which meant that she could hear and see sometimes but not others. In consequence, at times she felt they viewed her as a "fraud".

Janice Masters commented on the negative reactions from other people which she experienced as a dual sensory impaired person.

"Coming into contact with people, because when it comes to anything like cooking, reading, cleaning, these sort of general things, you can overcome them things on your own. I mean there's different gadgets and its all in your home anyway, there are ways of getting round it. But when it comes to being in the outside world meeting people,
there's not a lot you can do about it. You know it puts people off. Any form of disability people have got, it puts people off.”

Some dual sensory impaired people clearly felt marginalised not only from the hearing and seeing community, but also from those people who were single sensory impaired.

Some of the interviewees talked of adjusting to their situation, but at the same time of missing activities that they had previously engaged in, and/or being denied opportunities.

"You make the most of it that's all. Its upsetting and I know I thought it would never be me, but I got it and I just go on and make the best of my life, that's all I can do. "
(Henry Cramer)

"Sometimes I get fed up you know because its like being restrained in some respects."
(John Palmer)

John Brown was profoundly deaf and had developed a severe visual impairment in recent years. His life had changed dramatically and he had experienced a period of depression. He clearly missed being able to socialise with friends and the freedom of driving his car.

"Your life closes in, see. I say I try and be as cheerful as I possibly can. There's no good being otherwise...I mean, what can they do with a person like me at my age? I mean, at my age they might say you've had your life...As I say I'm not totally blind, see. I mean I've not had that taken from me. I've had my hearing taken from me but not my...I can see. I know your outline. I know you're there. I mean that's something to be thankful for isn't it?"

"I've learned to adapt to my disability and everything, but I'm on my own, you do feel left out of a lot of things." (Alan Woodger)

Some of the interviewees were experiencing changes both in their sensory abilities and their lifestyles. A small number of them expressed a great deal of concern about their sight and hearing deteriorating further. Alan Woodger, for example, was concerned that he would have to rely heavily on other people to do things for him, and that he would become a "burden". He felt as if he was a living time-bomb, dreading the time when his fuse would run out.

"It makes you upset because you're like on time. You know you're like a blooming clock. Every day that comes. You take it as it comes, you know."

Others, however, appeared to have difficulty coping. Bill Broadhurst, for example, was extremely concerned about his deteriorating sight, and felt very pessimistic about the future:

"Well they can't do anything to help me. And I can't see they can help people who are blind, because they are limited in what they can do aren't they?"
Two of the interviewees appeared to be experiencing severe depression, which incapacitated them and increased their dependence on their carers. David O'Brien had become very depressed on being told that nothing could be done to restore his sight. He had become withdrawn and never went out the house. He desperately wanted to see again. Ram Pancholi appeared to be very depressed during the interviews, and at one point said he would rather be dead.

Given our failure to address the needs identified in previous sections, it is not surprising that some of the interviewees experienced a sense of worthlessness and appeared to be depressed. It may be that some of the interviewees may have benefited from the opportunity to receive some kind of psychological support, such as counselling. Unfortunately, depression and low self-esteem may also be viewed as a natural consequence of the way disabled people are treated by our society. The best way to address the psychological needs of dual sensory impaired people may therefore lie in wider societal changes.

Current health and social care service provision

Interviewees were asked questions about their use of, and satisfaction with the services provided by health and social care agencies. Some of their experiences have been described in the previous section on needs; others are drawn out in this section. The general implications for the agencies are explored in the final section.

The Health Service

The Health Service is concerned with the diagnosis, treatment and evaluation of vision and hearing impairments. Most of the interviewees were reasonably satisfied with the health services that they had used. This was particularly the case with the older dual sensory impaired people. John Brown, for example, had had a great deal of contact with the Health Service in recent years, due to the deterioration in his vision and hearing and the heart attacks he had experienced. He was full of praise for all the staff he had come into contact with.

"...but I couldn't complain about the food or the nurses or the doctors or anybody.... They were good.... It was very difficult for the nurses, very difficult for the doctors and specialists because I couldn't hear what they were saying to me. But they all kindly wrote it down in large type, and my wife brought my glasses so I could read what they were asking me or what they were telling me. I mean, they couldn't be better than that, could they."

Molly Richardson commented that she had always

"found everybody very good and kind and considerate."

However, a small number of the older dual sensory impaired people appeared reluctant to pursue help and assistance for their sight and hearing impairments. There appeared to have been a variety
of reasons for this, including, for example, a reluctance to acknowledge the existence or effects of the impairments; and regarding the decline in their senses as a natural consequence of the ageing process. Sometimes, this latter attitude appeared to have been shared by professionals. Ram Pancholi, for example, had raised the issue of his deafness to his GP on several occasions and had been told that there was nothing wrong with his hearing. He had not been referred on to see a specialist.

Clinical diagnosis and treatment were provided by the specialist single sensory impairment services, the ophthalmology and ENT clinics. There did not appear to have been any understanding in either of these specialist clinics of the multiplicative effects of the interviewees' dual sensory impairments. The same single sensory approach appeared to be true for the low vision and hearing services which prescribe sensory aids. There was no evidence of co-ordination between these departments nor did there seem to be a cross-referral system to ensure that both impairments were always identified and thoroughly assessed.

Unfortunately, not all those who had sought medical help and advice appeared to have been well informed by the medical profession about the nature and prognosis of their impairments. As a result, some were confused about the time of onset of their impairments, and/or about the congenital nature of their impairments. For example, some of the interviewees may have experienced sensory impairment earlier than they believed to be the case. The time of onset of the impairment was sometimes believed to be linked to a particular incident; for example, Christine Bell stated that she became hearing impaired following a bout of measles at the age of nine years old; Henry Cramer said that he had become hearing impaired at the age of six or seven years old, following bad earache (his sister also had early childhood deafness and they both had retinitis pigmentosa); and Paul Ward's mother told him that he had damaged his eyes during a cycling accident, whereas his doctor had advised him that he was congenitally visually impaired.

Some of the adults appeared to have hereditary conditions; although no specific questions were asked about the hereditary nature of the impairments, approximately half of the interviewees mentioned relatives who had similar sensory impairments. These interviewees did not appear to be aware that they may also have had an hereditary condition.

The interviewees identified several reasons for this level of ignorance, and the accompanying distress and anxiety for some of them. In general, communication between themselves and doctors appeared to be poor; interviewees believed that this was partly because some health staff did not take the time or make the effort to give them information, and partly because they did not recognise and respond to their communication needs. Alan Woodger, for example, mentioned various difficulties and frustrations he experienced as a result of hospital staff, doctors, nurses, and receptionists failing to communicate effectively with him. They would talk quietly, mumble, cover their faces or turn away when speaking to him. Alan felt that Health Services staff should be given training in communicating with deaf people. He felt there should also be loop systems in clinics.

"Now if you're trying to be a nurse or doctor or whatever it is, put some sort of training in with the system, so that they are going to be able to cope with Deaf people."
Bernard Oakley found it very "awkward" in hospital as the staff did not always understand the nature of his disability. They would tell him their names but would then expect him to recognise them, which he was unable to do.

For those interviewees who were members of a minority ethnic community, communication difficulties with health professionals were particularly acute. Ram Pancholi visited the hospital frequently, but he and his wife had never been provided with an interpreter. His daughter, who spoke English, accompanied him to the hospital as often as she could. Ram felt that when he stayed in hospital he needed an Asian nurse. He would also have appreciated written information in Gujerati which his wife would be able to read.

A member of Manju Mehta's family, Saroj, also voiced the need for more Asian speaking staff or the provision of interpreters.

"We went to the hospital and she was totally confused as to what was happening. They did not have a single person on the staff who was speaking the language".

In addition to the failure of health staff failing to address their communication needs, some interviewees were critical of the doctors' attitudes and approach.

"I'm going up the Infirmary. I'm going to tell them. They can have a look at it. They might tell me. Sometimes they don't tell me. I have to ask the doctors, see... They don't ask me, sometimes. Sometimes he has to write a letter to me doctor. Then me doctor tells me. Fact he doesn't want me too upset." (Donna Philips)

"When I went once, do you know what the lady doctor said? 'Why do you come here?' I said 'Because I was given an appointment, that's why I'm here.' Well,' she said, 'there's nothing we can do for you.' That was it." (Christine Bell)

"It is important to be able to ask questions so that you do know what is going on. I mean in some cases it is even important to look at your notes so that you know what is going on. Especially when you can't hear properly. You don't always take in what they are saying. You don't say to them 'What did you say?' There are doctors down there that are capable of snapping at you, do you know what I mean? They're not all saints. That's why old people don't say anything. That's why they just sit there for hours, they don't say anything. They come out of the hospital still not quite sure what is going on. They're not quite sure what is wrong with them. They are probably not quite sure what they are supposed to do with the tablets and drugs they are taking." (Janice Masters)

"Attitudes of the doctors are terrible. You can't ask them any questions. They haven't got the time for you. Don't get me wrong, I appreciate what was done for me, but the attitude is wrong. You've got the right to ask questions..... a lot of the patients are
never told by the consultant what is wrong with them, and they are too frightened to ask and they come up home quite mystified." (Philip Hammond)

The consequence of the attitudes and approach of doctors was that the power differential of expert over patient was reinforced. One possible effect of such an approach is to deny people the opportunity to take control over, and responsibility for their own lives. For example, Janice Masters had always looked after the tubing on her hearing aid by unblocking it herself. Recently, however, she had been told that she should not be doing this, and staff at the Hearing Services Centre had glued the tubing to her aid. She was not very pleased about this, as it meant she had to go to the Hearing Services Centre every time her aid became blocked:

"It's like at one time I was always going down to the eye clinic, now I'm not going down there so often now. It's like I don't want to keep having to tramp down the hill to the Hearing Aid Centre either. It's like you want to live your own life rather than keep going to these places."

Some of the interviewees identified ways in which access to general health services were being denied to them. For example, some felt that the Health Services failed to consider their written communication needs. Hazel Simpson had been given written instructions by a doctor on one occasion, and being unable to read them, she had requested to know what they said. She was told to ask her husband. Alan Woodger found it very difficult to read instructions on medicine bottles, and felt that they should be provided in large print. The letters which Janice Masters received from the ophthalmology clinic were "very light grey on white paper", such that even sighted people found them difficult to read.

"I don't know what they're playing at when they send them sort of letters out."

A failure to meet cultural needs was also identified by one of the Asian interviewees. A member of Manju Mehta's family, Saroj, expressed a great deal of dissatisfaction with the service provided by the local hospital. Saroj wanted to stay with her relative all day and all night, but found staff to be unhelpful.

"I asked permission to stay and they were very rude to me."

Saroj had had to argue the case with each new set of day and night staff, and she was eventually allowed to sleep in the lounge. Halal food was provided for Manju, but nobody ensured that she was actually eating it.

"She doesn't like people to leave her. I think it's our cultural set up is like that. That we don't leave our old people alone at any time. They are so protected."

Saroj felt that there should be facilities provided to allow family members to stay, particularly for Asian people. She also felt that there was a need to improve professionals' understanding of
Asian culture. For example, when the time came for Manju to leave the hospital she was expected to undergo a "test" to see what she could do around the house.

"They weren't going to let her out because obviously she wasn't going to be able to lift her kettle and cooking and all that. But I said she doesn't need to do that in our house. She'll never be asked to fill a kettle. If you wait for that, you'll be there for ages, because she's not expected to do that kind of work."

Social care services

Social Service Departments have a legal responsibility to maintain registers of disabled people. For most disabilities, registration is not dependent upon an examination by the medical profession. Visual impairment, however, is unique, in that registration is based on medical opinion about an individual's degree of impairment. A system exists by which visually impaired people are certified by an ophthalmologist as meeting the criteria to be registered by the Local Authority as blind or partially sighted. A form (BD8) is completed and passed on to Social Services, who then carry out an assessment visit.

No such system exists for hearing impairment; there is no automatic referral from the Health Services to the Centre for Deaf People, who carry out work with hearing impaired people on behalf of Social Services. The possibility of registration as deaf or hard-of-hearing is generally not well-known, and carries few benefits; it is dependent upon an assessment by staff at the Centre for Deaf People.

The interviewees were asked about their use of, and satisfaction with Social Services, the Society for the Blind, the Centre for Deaf People, and the national voluntary agencies in the field.

1. Social Services

The majority had had contact with the Social Services Department at some time or other, most following their registration as blind or partially sighted, when they had been visited by a Social Worker for the Blind. The five interviewees who were not registered had not received a visit from a Social Worker for the Blind.

Only a small number were in receipt of help from this department on a regular, ongoing basis; this included a small number of older people who had assistance form a Home Carer, and one interviewee who attended a Day Centre. Ram Pancholi was the only interviewee who was not aware of the existence of Social Services, even though he had been registered as blind.

Some had received a single visit from a Social Worker for the Blind, whilst others saw the same local Social Worker on a regular, if infrequent basis. The latter group were positive about the help they received, particularly in respect of information about financial benefits.
"She is very good and she has come to see me when she gets time. It's been over a year since I've seen her. Mind you, she leaves her card so I mean if I want any contact you know, I've just got to get in touch with her." (Hazel Simpson)

"When I first lost my sight he came quite a lot. He helped... very much so, in more ways than one." (John Brown)

Alison Taylor's Social Worker used to visit her occasionally and she felt she was "very kind and helpful". She appeared to have worked hard on her behalf, liaising with other Social Service Departments and agencies, helping her to claim for certain benefits and to obtain various aids such as bath aids and a loud doorbell.

One of the people who did not have contact with a named Social Worker expressed a feeling of isolation. Jenny Broadhurst felt that there should be follow-up visits, possibly once a year.

"There is one thing that I think, I mean, surely these services, the Social Services and the Welfare, there is never any follow up. Nobody ever comes. Yes they register you, but nobody comes to see if things are all right, any problems or otherwise."

She felt that "even a phone call" would help.

2. The Society for the Blind

Registration as a Blind or Partially Sighted person resulted in interviewees being referred to the Society for the Blind, which provides a rehabilitation service to visually impaired people in Leicestershire on behalf of Social Services. The Society provides rehabilitation training, both on an individual and group basis, information and advice, aids for communication and daily living, and social groups and activities. Comments about these services have appeared in previous sections of this chapter.

Almost all of the adult interviewees spoke about the aids that they had received from the Society; a small number had also received training from Rehabilitation Officers in daily living skills or mobility; some had attended groups and a couple had been on "Society" holidays. Three of the adults who were born hearing impaired and whose vision was slowly deteriorating had not wanted any contact with the agency, but felt that they may need help in the future if their sight worsened.

"If I do want it I shall have it. But at the moment I'm still independent." (Henry Cramer)

"As I am now I'm not going to need that sort of equipment yet." (Alan Woodger)

Some of the older interviewees had had minimal contact with the agency, such as a one-off visit, but others attended social groups on a regular basis.
Interviewees generally expressed satisfaction and appreciation for the services provided by the Society, but as has been highlighted previously, these services are aimed at single sensory impaired people, and therefore did not always meet the needs of the people interviewed, nor were they fully accessible. For example, Hazel Simpson had tried to join a discussion group, but was unable to participate:

"In the afternoon you went into a group, one was an age group and one was a bygone group, put it that way, and I was lost. Because I'm no good. I mean I'm all right on a one-to-one, but if you sat over there I wouldn't hear you."

John Brown described his experience of attending the Centre shortly after he had been registered blind.

"When I was registered blind they had about half-a-dozen people down there the same as myself, who had lost their sight, see. And we had a day there, more or less a day there. They gave us a lunch and in the afternoon there were talks. Well, I couldn't hear anything, and they were also asking if we would like those radio information... you can send them by post, these tapes. But of course I couldn't hear anything, so it was no good at all."

There is no doubt that one of the benefits of registration as blind or partially sighted for some of the people interviewed was that it appeared to "open doors" to other services, of which they might not have been aware, or to which they might not otherwise have had access. For example, only the people in this study who were registered had had contact with the Society for the Blind. However, it is suggested that conversely those who were not registered were not gaining access to services which may have benefited them.

3. The Centre for Deaf People

The Centre for Deaf People provides a social work service, advice and information, aids and equipment and social groups. Fifty percent of the adult and older interviewees had had contact with the Centre for Deaf People; of the remainder, some adults were aware of its existence, whilst many of the older people were not. As in the case of the Society for the Blind, interviewees' detailed comments on the services provided by the Centre have appeared in previous sections. Those interviewees who had made use of these services generally expressed their appreciation for the help they had received. Susan Howard, for example, was visited by a Social Worker from the Centre for Deaf People. They communicated using British Sign Language. Apart from her mother, the Social Worker appeared to be the only other person with whom Susan communicated. Although this took place infrequently, Susan clearly appreciated the limited contact that she had with this worker. Manju Mehta and her family had been visited at home by a member of the Centre staff, and given advice about hearing aids and other aids and adaptations; they had found this very helpful.

Critical comments were made about the fact that aids from the Centre were not always free of charge, nor was assistance in their use and installation always given. Two of the interviewees had received
loop systems from the Centre; although Alan Woodger was very appreciative of it, he had had to pay half the cost of his loop system despite being on Income Support, and had been left to install the system himself, and did not appear to be very sure how to tackle this task. Nevertheless, Alan but felt that the agency were doing the best that they could given the funding they received.

Like the Society for the Blind, it was clear that the Centre's services were also aimed at single sensory impaired people. For example, staff did not always seem to show an understanding of the effects of dual sensory impairment, and there was no evidence of consideration being taken of interviewees' need for information in accessible formats. It was concerning that the majority of the interviewees did not appear to be aware of the existence of various aids and adaptations, such as vibrating pillows, alarms and pagers, which could have been of benefit to them.

4. Co-ordination between service providers

It is not surprising, given the single sensory approaches adopted by service providers, that social care assessments appeared to have been undertaken from a specialist viewpoint, and were not holistic in approach. There also appeared to be a lack of cross-referral between agencies, with the consequence that people were denied access to help and services from which they may have benefited.

Where several professionals were involved, they did not appear to co-ordinate their response. This failure to work together can cause confusion; for example, Susan Howard had been experiencing deteriorating vision for some years, and following her registration she was suddenly visited by a number of different professionals. Some of them could not communicate with her. She did not understand what was happening.

"She couldn't understand why all these people were coming all of a sudden. They all pounced, do you know what I mean. There was three of them all coming in one week. She didn't know who the hell they were. When they had gone she kept asking me who they were and why they had come, and this and that. I tried to explain to her. It was very hard to explain to somebody. We didn't actually tell her what was wrong with her, we just said her eyesight was getting poor. She doesn't like change. When people stopped coming all of a sudden it hit her." (Susan Howard's mother)

5. The national voluntary agencies

A range of information, advice and rehabilitation services are also provided by national specialist agencies for visually impaired, hearing impaired or dual sensory impaired people such as the Royal National Institute for the Blind (RNIB), the Royal National Institute for the Deaf (RNID), Sense, and the National Deaf Blind League (NDBL).

Generally, the interviewees had had no or little contact with these voluntary agencies.
WIDER IMPLICATIONS FOR HEALTH AND SOCIAL CARE SERVICE PROVIDERS

Previous reports have argued that dual sensory impaired people have “fallen through the gap” between the separate services designed for Blind and Partially Sighted people and Deaf and Hard of Hearing people. This study also found this to be the case. Health and social care services were geared towards those with a single sensory impairment and appeared to have failed dual sensory impaired people.

“It's all right Mum seeing one specialist in an eye clinic and another specialist in a hearing clinic, but where do the two things come together?” (Susan Tyler, a Carer)

“You see they know what to do with the blind, they know what to do with the deaf but they don't know what to do with the two” (Hazel Simpson, a dual sensory impaired interviewee)

The simplistic solution may seem to be to create a new specialist service for dual sensory impaired people. However, there is a real danger that the current medical model approach embraced by most agencies would lead to misguided attempts to rigidly define and categorise dual sensory impaired people, and to expert-led assumptions about their “needs”.

There are three reasons why the medical model approach is fundamentally flawed. First, dual sensory impaired people are members of an extremely heterogeneous population with the same needs as hearing and sighted people. They differ only in terms of their requirements to achieve satisfaction of their needs. Second, these requirements will vary from individual to individual, and so no stock solutions can be applied. Third, the satisfaction of dual sensory impaired peoples' needs is not the sole responsibility of health and social care agencies, but of society in general.

Nevertheless, health and social care agencies clearly need to improve their poor response to dual sensory impaired people. In this respect, two considerations are important. First, it is argued that the main focus should be on improvements to mainstream health and social care services, although certain specialist resources should also be developed. Second, these agencies need to shift from a narrow focus on the effects of impairments and functional ability to an approach which aims to empower dual sensory impaired people. Their aim should be to reduce the social and environmental barriers which dual sensory impaired people face, thus enabling them to participate in society on an equal basis with others.

Improvements to mainstream health and social care services

Various areas need to be addressed to improve service provision for dual sensory impaired people including formally recognising their existence; improving professionals’ awareness and understanding of dual sensory impairment; ensuring access to health and social care services; carrying out individual assessments of need and ensuring a flexible service response; better co-ordination of services; and improved information provision for dual sensory impaired people.
Formal recognition of the existence of dual sensory impaired people

One of the arguments put forward to explain the failure to develop appropriate services has been the lack of a clear definition of dual sensory impairment. Experts in many countries have long argued over the best way of defining dual sensory impaired people. Some people, such as members of the North Regional Association for the Blind have argued for a rigid definition based on measurements of visual acuity and decibel loss. Such a medically-based definition excludes certain people, such as those with cognitive impairments, and fails to take account of functional abilities and environmental influences. Rigid definitions also lead to concerns about who to include. At the beginning of the project the researcher frequently encountered the phrase "But is he/she really deafblind?". It appeared that an assumption was being made that people either had to conform to a stereotypical image of a deafblind person or they had to be single sensory impaired.

This study has shown that the reality is that dual sensory impairment is a continuum, with dual sensory impaired people experiencing varying degrees of combined hearing and vision impairments. As Dorothy Entwhistle stated at a seminar in Birmingham concerning the formation of a UK Coalition on Deafblindness:-

"If a person is in need of a service, does it matter that he or she can hear a decibel or two too much or that they can recognise a letter A an inch too far away? Must we quibble about such measurements, especially when each is taken in isolation, without a thought to the interaction of the two sensory losses? So whatever definition may eventually be decided upon, it must ensure that "those people in need of services obtain them." (Deafblind Services Liaison Group, 1994).

It is nevertheless extremely important to adopt a definition or description of dual sensory impaired people in order to recognise their existence; to acknowledge their needs; and for the planning, development and improvement of services. It is argued however that the definition should not attempt to rigidly define an extremely heterogeneous group of people and that individuals who have a combined vision and hearing impairment should be described quite simply as dual sensory impaired. In common with other impaired people they are disabled by:

"the loss or limitation of opportunities to take part in the normal life of the community on an equal basis with others due to cultural, physical and/or social barriers. (DPI,1981)

Improving professionals' awareness and understanding of dual sensory impairment.

During the first phase of the study the researcher identified a lack of understanding amongst many professionals and attempted to raise their awareness by the dissemination of written information, and through giving talks. There would appear to be a need to provide information and training to single sensory impairment specialists and to the many different staff groups in the various settings within the health and social care agencies. As Vernon and Duncan (1990) state:-
"Unless their hearing and visual impairments are properly diagnosed and the implications of their dual sensory impairment understood by everyone involved, deafblind individuals receiving services designed for other populations are almost certainly suffering from inadequate care (for example a lack of meaningful communication and interaction with their environment)."

It is suggested that professionals need to be alerted to the importance of identifying impairments as early as possible, and of encouraging people to have their sight and hearing checked. Early detection can lead to help and minimising the consequences of the impairments.

Given the prevalence of dual sensory impairment amongst older people, it is particularly important that specialist advice which aims to improve their knowledge and skills is given to those working with this group. Older people may not notice a gradual decline in their senses, or may want to deny or minimise the potential seriousness of the problem. They may have a tendency to accept sensory decline as inevitable, and to believe that nothing can be done. As Balder (1994) states:-

"Awareness is important because deafblindness as a handicap often isn't recognised. That phenomenon especially occurs when the handicap reveals itself later in life. In such cases it's usually an insidious and progressive process in which someone's sight and hearing becomes slowly worse and worse... When the double sensory handicap "deafblindness" isn't recognised - that is if one isn't aware of this handicap - the person in question becomes needlessly and severely isolated. After all he doesn't get the care he needs, doesn't learn the alternative ways of communication, etc. And in particular with senior citizens - who as they grow older - will find it more difficult to learn new skills, it's of major importance to spot deafblindness in time; "awareness" can prevent a lot of problems. It is clear that it is of extreme importance that "they" (everyone who can come in contact with deafblind people) are aware of deafblindness."

A failure to recognise the effects of dual sensory impairment can lead to people mistakenly being regarded as "confused".

"Most demoralising to the older person with sensory deficits is misdiagnosis as senile, incompetent, or demented. Often when an older person appears confused, disorientated and unable to answer questions quickly enough, the actual problem is related to impairment of vision or hearing. (Wolanin and Philips, 1982)

The researcher personally witnessed professionals reaching such a conclusion as a result of their own difficulties in communicating with a dual sensory impaired person.

It is argued that the aim of professionals should be to help older people develop strategies for "successful ageing", and to ensure their full inclusion in community activities so that they can continue to live active, participative lives.

**Improving the accessibility of health and social care services**
This study has shown that much could be done to improve the accessibility of services for dual sensory impaired people. The failure to consider their needs had, for example, resulted in some dual sensory impaired people being unable to fully participate in activities on an equal basis with others, and some being just as isolated at a day centre as they would have been at home.

It is argued that agencies need to ensure equal opportunities in service delivery and it is suggested that as a first step towards improving accessibility, one action that could be undertaken is the commissioning of an access audit. Such an audit could include consideration of environmental issues, such as the provision of loop systems, the use of colour contrast, lighting, clear signs and the training of staff in sign language, communication skills and methods, as well as the provision of information in appropriate media.

Carrying out individual assessments of need and ensuring a flexible service response.

It has been suggested that the medical model approach to service provision leads to the categorisation of people, and subsequent generalisations and assumptions are made about the needs of people belonging to different categories or groups. Such generalisations may not match individual experience.

The point was well made by R. Humphries, writing in Community Care.

"Mechanisms for determining what services Social Services Departments should provide have not developed by pooling individual assessments of need (bottom up), but through (top down) preconceived ideas about what model of service is appropriate for a client group. So a national map of services is a landscape dominated by standardised services, often inappropriate to the needs of particular individuals". (Humphries, 1992).

This study has shown that although the people interviewed clearly shared some common concerns and needs, there was also a tremendous variation in their experience, situation and the needs they expressed. They are a heterogeneous group who require a flexible response from service providers on an individual basis.

These assessments need to be holistic,

"which therefore considers the person in the round, balances the relative influences of both the person (their needs, abilities and aspirations) with their environment (cultural, social, emotional, and physical)." (Department of Health, 1991a).

It is also important that they are undertaken by professionals who fully understand the nature of dual sensory impairment and have the necessary communication skills.
Given some dual sensory impaired people's low expectations for themselves, and their restricted access to information and communication difficulties, some may need personal help in articulating their needs and pursuing their choices. Some may therefore require access to an independent advocate.

One of the benefits of the new care management approach is the flexibility it allows. Properly carried out assessments have the potential to lead to innovative individual service responses and a more co-ordinated approach by service providers.

Improved co-ordination of services

This study has shown how the historical fragmentation of services has led to dual sensory impaired people not having their needs met by the single impairment agencies. It is suggested that the isolation of professionals in different departments and agencies needs to be reduced, not least because they often have to co-operate closely together to help meet the needs of dual sensory impaired people. To perform their role effectively, each agency needs to be well informed of the relevant resources that are available, and the role of other agencies and other workers. This has implications for training and the flow of information.

It is suggested that all agencies need to consider new ways of co-operating together to meet the needs of dual sensory impaired people more effectively. It would seem from the findings of this study that particular attention needs to be given to improving the referral systems between health and social care agencies, in order to ensure access to help for those who need it. Along with Willetts (1994), it is suggested that people should be referred to a service at the time when they need or would benefit from it, rather than on the basis of registration. As he states:-

"The notion that social care starts only when health care ends is imprinted on the pattern of service provision and is long overdue for abandonment. Earlier social care intervention, however, requires policies which acknowledge its values, and processes which permit it to happen. It also required from the key community carers, such as GPs, the willingness to refer some people for social support assessment at the same time they are referred to the ophthalmologist"

A medically based registration system does not exist for hearing impairment but the issue of ensuring good cross referral systems is the same.

Some moves have already been made to ensure a more co-ordinated and collaborative response. The Society for the Blind, for example, has recently arranged for staff from the Hearing Services Centre to undertake joint clinics with the optometrist who prescribes Low Vision Aids. Initiatives of this kind would seem to be indicated.

A further way to develop a co-ordinated approach could be to establish a Senior Social Services Manager to be responsible for ensuring multidisciplinary working. This was recommended in the Department of Health (1989) report.
"A designated senior officer within the local authority should be appointed to be responsible for services for deafblind people to ensure that multidisciplinary advice, help and assessment is made available."

Such a role is a particularly vital one in Leicestershire, where several agencies provide the Social Work and Rehabilitation services to hearing and visually impaired people. The Senior Social Services Manager could be responsible for ensuring that dual sensory impaired people are always included on the agenda along with single sensory disabled people, and that a network of professionals with appropriate skills is developed.

On-line data banks containing shared information about local service provision could be provided for all statutory and voluntary agencies. This data bank could also serve as a service user index, giving details of age, impairments and so on, which would assist multidisciplinary working.

The provision of information to dual sensory impaired people

One of the factors which can help redress the power imbalance between dual sensory impaired people and professionals is the provision of information to enable people to make informed choices.

"Information is now widely recognised as the key to helping dependent older people and their carers to improve the quality of their lives in the community." (Tester, 1989)

Dual sensory impaired people are particularly powerless in this respect. Many of the dual sensory impaired people interviewed seemed ill-informed about their disability, the aids that may have assisted them, and the services and resources available to them locally and nationally. It is suggested therefore that service providers critically examine their information provision and take action to ensure its accessibility.

Dual sensory impaired people need information which is user friendly in appropriate formats such as large print, Braille, tape, BSL, video, etc. provided at key points in time such as on initial contact with a service, and which is easily accessible, for example at local information points in ethnic minority languages.

The development of new specialist resources and services

Although changes and improvements to existing service systems should bring increased benefits for dual sensory impaired people, this study found that there is an additional need to develop new local specialist resources, namely specialist workers and a Guide Communicator Service.

The development of specialist workers

The establishment of specialists posts could enable the provision of some specific services which would appear to be of benefit to dual sensory impaired people, such as advice, support, and
counselling, the teaching of communication skills and methods and British Sign Language, the provision of rehabilitation services, including daily living skills training and mobility, the provision of specialist aids and equipment, the development of volunteer visiting schemes, and the promotion of opportunities for personal development and social stimulation. These latter might consist of assertiveness and confidence building groups, self-help groups, developing peer support networks, and groups to encourage self-advocacy. It is suggested that these workers could be single impairment who have received additional training to undertake this work.

These specialist workers could also provide information, advice and training on dual sensory impairment to those staff working in mainstream health and social care agencies and also act in an awareness-raising role to other community services and the general public.

It is argued that there is a need for more relevant information and training materials on dual sensory impairment to be developed by the national voluntary agencies in the sensory impairment field. There is a particular need to develop these resources in respect of older dual sensory impaired people.

**A Guide Communicator service**

This study has shown that dual sensory impaired people can experience extreme isolation from the everyday world around them, and that their ability to act autonomously can be threatened by their over-dependence on other people. It has been suggested in previous sections of this chapter that one possible answer would be the development of a new personal assistant service. A Guide Communicator service could help to:

- relieve extreme isolation
- retain independence (possibly preventing unnecessary early admittance into residential care)
- provide access to community services
- enable dual sensory impaired people to express their needs
- give respite relief to families and carers
- bring about a more cost effective use of current resources by relieving professionals from the undertaking of time consuming tasks such as teaching communication methods.

Guide Communicators may undertake a range of duties including, for example, enabling an individual to join community groups, assisting with correspondence or escorting a person shopping. A volunteer scheme has recently been developed by the Society for the Blind, however it is suggested that formal recognition by the Social Services Department is required of dual sensory impaired people's need for personal assistance. It is suggested that the service required would need to be flexible, based on individual needs, and be undertaken by paid and trained staff.

**The adoption of a new empowering approach to service provision**

It is argued that that health and social care agencies need to adopt a new and empowering approach to their service provision. Five strands can be identified for inclusion in this approach; agencies need
to espouse an explicit model of disability which more accurately reflects the experiences of disabled people themselves; to ensure an anti-discriminatory approach; to adopt a partnership approach with service users at every level from individual needs assessments to the planning of services; to be very clear about the meaning of independence; and to develop a campaigning role to improve access to community facilities.

The model of disability and anti-discriminatory practice

It is important that the model of disability which is adopted recognises the wider societal barriers which disable people with impairments. It is speculated that professionals at present tend to see people's "problems" as resulting solely from their impairments; disabled people themselves are much more aware of environmental and social influences. The adoption of a model of disability which recognises the environmental and social factors which cause disability could have a profound effect on the way that professionals operated. As the Hear Me, See Me report (Department of Health, 1991a) states:

"If agencies moved towards a social model of disability, then indirect work (which includes an appraisal of cultural influences on a practitioners attitudes and behaviour) become crucially important. Such indirect work will also involve examining the parts played by the practitioner's own agency, other agencies, families and local communities in achieving or impeding a more integrated life-style for all citizens. This reflection could and should mean that, subsequently, those practices and attitudes which marginalise, patronise and so disempower certain people are challenged."

Clearly, it would be important for this model to be negotiated and shared between the statutory and voluntary agencies; and for it to inform service objectives and policy, procedural and practice guidelines. All professionals would need to receive training on the model and the implications for their practice. Such disability equality training should help them understand the disabling effects of society and how their own attitudes and approach can in themselves be disabling.

This study has identified that most dual sensory impaired people are older, and that some of the negative attitudes they experienced were age-related. It is argued that ageism also should be challenged by anti-ageist practice training.

Some disabled people clearly experience multi-discrimination on the basis of other factors such as gender and ethnicity. It is argued that these elements need to be addressed within an anti-discriminatory framework which recognises the disadvantage and oppression which people experience on the basis of such factors as ethnicity, gender, and sexuality, along with age and disability.

Partnership with service users

One of the fundamental characteristics of the medical model approach to service provision has been its emphasis on objective assessments of disabled people's needs by "experts". It is argued that the
imbalance of power between expert and consumer can all too easily create or reinforce dependency and helplessness; certain writers argue that the employment of professionals who act as "experts" on disabled people's "special" needs is in itself oppressive. As Gomm (1992) put it:

"Misguided ideas about disability, especially when voiced by supposed 'experts' do immense damage to the lives of disabled people. As long as policies and services are based around such theories which do not truly represent the experiences of disabled people, the resulting services will never meet our real needs. Needs which, at the most general level, are usually not so "special"; needs which are in truth usually the same as most people's."

Proponents of the social model of disability have argued that disabled people themselves should define their own needs, as opposed to "experts" defining their needs for them; see, for example Oliver, (1983, 1985, 1990). They have argued that professionals should instead adopt the role of a facilitator or act as a resource:

"The professional must change from being the expert definer of need and rationer of service to a resource which the disabled person may negotiate to use as s/he chooses." (Department of Health, 1993)

It is suggested that professionals need to acknowledge far more the felt needs of individuals, and recognise that that they are not experts on people's lives. A recent study by Partridge, Johnston and Morris (1991) on the needs of older people emphasised that an individual's attitudes and beliefs about him/herself were a crucial factor in influencing their expressed need for services:

"It has been shown in this study, as in others, that patients perceptions are not always congruent with objective assessments. The way that people view their problems and cope with them are central issues in deciding their need for services... The goals of any interventions must be explicitly related to individually perceived needs."

Although it is critically important for professionals to be guided by how individuals view their own needs, it is also true to say that simply asking people what they need has its limitations. Previous research has shown that people's perceptions may have a biasing effect on how they view their own needs. For example, Runciman (1966), in his study on deprivation, discovered that the poorest sections of society were hardly aware of their poverty. Similarly, a study of dual sensory impaired people in Norway found people to be socially isolated and many leading very passive lives; nevertheless, fifty-eight percent of these people expressed satisfaction with their situation.

"There seems thus to be a discrepancy between the objective situation of the deafblind and the high level of expressed satisfaction." (The Health Services of Norway, 1976/77)
It should not therefore be surprising that many of the people in this study, who appeared to lead quite restricted lives lacking in opportunities, in general appeared to be fairly satisfied with their situation and with the services that they had received.

One explanation for this is that the dual sensory impaired people interviewed may have accepted society's negative attitudes towards disabled people. These focus on inabilities, stress dependency and passivity, and tend to deny that disabled people should be able to participate fully in society. Similarly, the older dual sensory impaired interviewees could have been influenced by society's ageist attitudes towards older people, which also stress dependency and passivity.

Another factor which may have influenced the needs they expressed was their lack of knowledge and awareness of their rights and entitlements, and of the help potentially available to them. This would have restricted their ability to speculate about what help they needed. As a result, the interviewees seemed to accept their situation, and had very low expectations, both of themselves and service providers, and generally did not suggest innovative ideas for service provision.

What appears to be needed therefore is a partnership between professionals and dual sensory impaired people, with professionals listening to dual sensory impaired people, gaining an understanding of their personal experience, sharing with them their knowledge and information and agreeing goals and solutions based on their felt needs.

Involving disabled people in service provision at all stages could also improve the situation. They could be involved in the planning, design and implementation of services, and in quality assurance exercises. It is suggested that this would lead to the establishment and development of satisfiers which are based on the actual experiences of dual sensory impaired people, and which should therefore better meet their needs.

"It is a matter of offering people a real sense of involvement so that they begin to experience a closer relationship between their needs and services." (White, 1988)

Given the heterogeneity of this group it would be important to ensure that several different people are consulted and that such exercises are not tokenism. The experience of the researcher in working with service users on a planning group would point to the importance of offering disabled people training to enable them to take on this role and of providing professionals with training in working with service users.

The nature of independence

Service providers need to give consideration to the meaning of independence. Currently, the general aim of rehabilitation services is to provide aids and skills training to enable the individual to function independently; that is, as near as is possible to the way a "normal" sighted and hearing person would behave. This approach is reflected in assessment forms with their emphasis, for example, on a person's ability to undertake self-care activities.
While it is clearly unsatisfactory to be unnecessarily over-dependent on another person, like French (1991), it is argued that independence is not about being able to undertake functional tasks alone, but about being in control of one's own life, and being able to make decisions and choices.

"Narrowly defined, independence can give rise to inefficiency, stress and isolation, as well as wasting precious time. Striving for independence and normality can lead to frustration and low self-esteem. An over-emphasis on basic independence can rob disabled people of true independence by restricting their freedom of thought and action."

In this study, for example, some people expressed a preference for their partner or carer to undertake certain tasks on their behalf, rather than struggle to do them alone; and some preferred to take taxis rather than attempting to walk independently to their destination. Independence for some dual sensory impaired people may therefore mean using another person to assist or undertake tasks for them under their direction.

The development of an advisory and campaigning role to improve access to community services for dual sensory impaired people

Local and national organisations for visually impaired and Deaf and hearing impaired people have existed for many years, and dual sensory impaired people have always been regarded as a small, minority group of marginal concern. This study has shown that this is far from the truth. It is argued that they need to play a much greater role in advocating and campaigning on behalf of dual sensory impaired people to improve their access to community services.

"There is a common responsibility incumbent upon all workers in health and social care to be alive to the socially handicapping factors which all blind and partially sighted people experience on a day-to-day basis. Furthermore, it should be a key duty of some of these employees to campaign actively for employment and educational opportunities, and for accessible buildings, streets and transport." (Willetts, 1994)

It was the researcher’s experience during the course of the study that general community service providers were increasingly interested in ensuring access to their services for disabled people. However, they needed to be provided with information and training; local and national agencies could advise on the following issues:-

- increasing awareness and understanding of dual sensory disability

- challenging discriminatory attitudes and practices

- providing training in communication skills and methods
• making environmental improvements and adaptations, such as the use of colour contrast, tactile signs, loop systems etc.

• providing information in appropriate formats such as large print, tape, Braille and British Sign Language on video

• providing interpreters and Guide Communicators.

CONCLUSION

This study has shown that dual sensory impaired people are being disadvantaged by the failure of health and social care agencies to address their needs. The changes required to rectify this situation, including improvements to mainstream service provision and the development of some specific, specialist resources have been outlined above.

However dual sensory impaired people's needs are not "special"; they are the same as sighted and hearing people's - a job, adequate income, access to leisure opportunities and so on. Wider societal changes are required to enable them to participate fully in society.
CHAPTER FOUR

CONCLUSION
CONCLUSION

This study, by means of both quantitative and qualitative methods, has attempted to increase understanding of the nature of dual sensory impairment and the needs of adults and older dual sensory impaired people. The study was informed by Doyal and Gough’s theory on need and by a social model of disability. The implications of the findings for policy makers and for health and social care service providers have been drawn out.

The study comprises the most extensive local survey undertaken to date in Britain to identify dual sensory impaired people, and has produced some interesting and informative descriptive statistics on this population. The findings have challenged current thinking about the nature and extent of dual sensory impairment. It has provided some useful lessons for other researchers who may be considering undertaking similar survey work of this kind in the future; and through carrying out the study has begun the process of increasing awareness about dual sensory impairment amongst local professionals.

The research that has been undertaken in the past into dual sensory impaired peoples’ needs has generally been undertaken from an “expert” perspective and has been concerned with educational and rehabilitation needs. This study has adopted a new approach by undertaking a qualitative survey to try to understand the daily life experiences and needs of dual sensory impaired people and it has provided a very significant contribution to the scant literature currently available on the lives of adults and older people. It has revealed the failings of the current single sensory approach to service provision of health and social care agencies and has made suggestions for improved service delivery which will inform both policy makers and statutory and voluntary service providers. Finally it has added to the currently available literature on disability and need.

However this is exploratory and pioneering work and there is clearly a need for further research in this area. In particular there is a need for secondary analysis of the OPCS Disability Survey (1988) data and epidemiological survey work on dual sensory impairment; and for further studies on the experience and needs of dual sensory impaired people, and their carers. It is argued that there needs to be a reversal of the trend to study single sensory impairment in isolation and recognition of the impact of a combined vision-hearing impairment particularly when studying the experience of older people.

It is speculated that the historic reliance on a medical model approach to disability has led to much responsibility being placed on health and social care agencies to meet the “special” needs of disabled people. There appears to have been an emphasis on definitions and categorisation, and a consequent tendency to stereotyping and making assumptions about the needs of “groups” of people. Linked with this, staff have specialised in working with particular groups, and have undertaken partial assessments from the perspective of their particular training. It seems that the focus of attention has often been placed on the impairments and the carrying out of physical tasks whilst social and environmental factors have been ignored.
The consequences of this approach for dual sensory impaired people have been severe. The service structures, geared towards single sensory impaired people (deaf or visually impaired) have not allowed for the existence of dual sensory impaired people, let alone begun to address some of their needs. The perpetuation of the Deafblind stereotype has led to a failure to recognise the existence of the majority of dual sensory impaired people, who are neither single sensory impaired or totally deafblind, but who experience a range of combined vision and hearing impairments. Staff across both generic and specialist agencies alike generally fail to understand the nature of dual sensory impairment. Dual sensory impaired people, therefore are denied or experience restricted access to the very services that are set up to “help” disabled people.

This study has found much larger numbers of dual sensory impaired people than those revealed by other local surveys, but also significantly fewer than epidemiological studies would suggest. These numbers may therefore still be an underestimate of the true size of the population. The vast majority of those identified were older people; seventy-eight per cent were aged over seventy-five. A significant number of sighted and hearing people will become dual sensory impaired in later life, and of course, many single sensory impaired people can also expect a decline in their other sense as they grow older. As the numbers of older people are increasing rapidly, these changes and trends clearly need to be acknowledged by service providers, and should inform the planning and development of services.

The findings are also a direct challenge to the “low incidence” disability argument put forward by some professionals. Certain conditions which can cause dual sensory impairment, such as maternal rubella or Ushers Syndrome, are infrequent in occurrence; the large numbers of dual sensory impaired people found in this study were accounted for largely by older people, while the increase in the number of children born with multiple impairments reflect changes in epidemiology over recent years.

The perpetuation of the myth of the stereotype does a disservice to the large numbers of people who do not match it. The dual sensory impaired population is an extremely heterogeneous one, comprising individuals with very varied experiences, and life situations. Trying to rigidly define this group is unhelpful, and can lead to the making of collective assumptions, with a consequent failure to recognise individual experience. As the Department of Health state:

“No definition can be suitably apt to convey the magnitude of dual sensory impairment”.(Department of Health, 1989).

There needs to be a move away from describing people as deafblind or single sensory impaired, and recognition that there is a large number of people who could be more accurately described as people with a combined vision-hearing impairment i.e. dual sensory impaired. They may have varying degrees of impairments, from mild to severe; some may have additional impairments; and some difficulties in processing information due to old age, or learning difficulties etc. What they may experience in common are difficulties in communication, and the carrying out of everyday tasks.

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While dual sensory impairment is undoubtedly associated with functional limitations, which can be extremely severe, it is argued that it is our failure to address their needs which has resulted in dual sensory impaired people experiencing severe disadvantage and a reduced quality of life. For some, it has meant lives devoid of stimulation with consequent ill effects on mental and physical well being. As Bettica (1977) stated:

“As depriving as the double handicap is, deafblind people have suffered more from the attitudes of those around them and society in general, than the handicap itself.”

Service providers, and the wider public need to appreciate this, and to recognise their responsibility to address dual sensory impaired people’s varied communication requirements and other needs in order to ensure their access to society.

Doyal and Gough (1991) offer a theory of human need which could inform a more enlightened approach. They argue that physical health and autonomy are the two basic human needs. For them, autonomy centres on the opportunity to engage in some form of socially meaningful activity; to be denied the capacity for potentially successful participation in society is to be denied one’s humanity. Dual sensory impairment threatens people’s ability to interact with others and to participate in events going on around them. This is the case for those with more moderate impairments as well as for those with severe impairments.

Dual sensory impaired people of all ages have a right to an ordinary life and to be able to participate fully in society on an equal basis with others. Their needs are common to all of us; for example, an adequate income, educational and training opportunities, a job, social and leisure opportunities, access to transport and so on. However, they may have different or additional requirements in order for these needs to be satisfied, such as the use of a Guide Communicator. Many of the dual sensory impaired people interviewed in this study appeared to have been denied the necessary resources and opportunities to participate as full members of society. However, as Doyal and Gough argue, living is different from survival, and the social isolation experienced by dual sensory impaired people is uniquely cruel. Health and social care agencies need to be proactive in countering their isolation, and facilitating their involvement in the community; they need to provide dual sensory impaired people with opportunities to maximise their autonomy.

It has been argued that in order to achieve this, health and social care agencies need to address several issues within their current service provision and to develop some new specialist local resources. The issues to be addressed include, adopting a new empowering approach to service provision; recognising the existence of dual sensory impaired people; carrying out health promotion work; undertaking individual holistic assessments and adopting a care management approach; carrying out staff training; improving co-ordination and collaboration between agencies; and addressing access issues.
An empowering approach

It is argued that service providers should adopt a more empowering approach to service provision which aims to reduce the social and environmental barriers which disabled people of all ages face to enable them to participate in society on an equal basis with others. Four tasks have been identified which need to be addressed:

- to consider the model of disability which underpins their service provision;
- to consider the meaning of the concept of independence;
- to work in partnership with disabled people both on an individual and planning level;
- and to adopt a more campaigning role within the community.

The model(s) which underpin service delivery and practice need to be made explicit and it is suggested that all agencies adopt a social model of disability. Awareness of the issues of race, culture, gender, age and sexuality would also need to be included, and be reflected in policy and practice guidelines. Consideration also needs to be given to the meaning of the concept of independence. It is suggested that this is not concerned with the ability to undertake functional tasks alone but about being in control of one's own life.

A partnership approach to service planning and to the carrying out of individual assessments should lead to services being better informed about dual sensory impaired people's needs. However, given the heterogeneous nature of the dual sensory impaired population, several different representatives would need to be consulted with regard to the planning and delivery of services. Training and support is also likely to be required by some individuals to enable them to carry out this work and professionals are also likely to benefit from training in working with service users. Service providers could also ensure that they are better informed about dual sensory impaired people's needs by carrying out quality assurance exercises and employing dual sensory impaired people.

Finally it is suggested that an empowering approach to service provision could also include adopting an advisory and campaigning role to help improve opportunities and access to community facilities and services for sensory impaired people.

Recognition of dual sensory impairment

It is clearly critically important for all agencies to formally acknowledge the existence of dual sensory impaired people. However it is argued that undue effort should not be spent trying to rigidly define and categorise this heterogeneous group of people, either by clinical or functional descriptions. It is suggested quite simply that a separate group of people be recognised who are not single sensory impaired i.e. deaf or visually impaired but who have a dual sensory impairment. They, in common with other people with "impairments" are disabled by
“the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others, due to the cultural, physical and/or social barriers within society” (DPI, 1981)

It is suggested that dual sensory impaired people’s existence be formally recognised at all stages of service provision. This would include the drawing up of clear strategic plans to meet their needs and explicit policies and procedural and practice guidelines; improving referral and assessment forms to include dual sensory impairment and details of communication requirements; and improving recording and data collection systems. It is suggested that whenever the existence of deaf or visually impaired people are recognised so should the existence of dual sensory impaired people.

Historically, dual sensory impaired people have been described as “falling through the gap”. This situation could be reversed by affording them greater priority in service provision and deliberately directing resources towards them. For example the Health Authority could ensure that all visually impaired hearing aid users are prescribed with the best aids possible in recognition of their need to maximise their hearing and be prescribed with two aids if appropriate.

Health Promotion Work

This study has suggested the need for health promotion activities to be undertaken with regard to identifying sensory impairments and screening “at risk” groups. There appears to be a need to increase the awareness of individuals themselves about having their sight and hearing checked; and the awareness and understanding of carers and professionals. Certain groups such as those with learning difficulties, and older people, particularly the “old, old” would appear to benefit from screening to identify impairments. Another group which it is suggested may benefit from some outreach work to raise awareness about sensory impairments are the minority ethnic communities.

Care Management Approach

Recent legislation, in the form of Community Care legislation, could provide opportunities for an improved response by service providers to the needs of dual sensory impaired people. This legislation proposes a new care management approach which encompasses the carrying out of individual holistic assessments followed by the provision of individually designed “packages” of services. Such an approach is a move away from the “stock solutions” of the past and should allow for far greater flexibility in service response. This research has shown a wide variation in the situations and experiences of dual sensory impaired people and an individual, flexible service response is vital.

The assessments are also expected to allow for far more involvement of the user and carer, adopting a partnership approach to assessments of need which this study has argued for. (However, given their restricted access to information and communication requirements, it is suggested that some dual sensory impaired people may benefit from the support of an independent advocate). Clearly these assessments would need to be undertaken by professionals who have an understanding of dual sensory impairment and who can communicate effectively with the service user, either directly or
through a Human Aid to Communication. (HAC) They would also need to be undertaken within the context of a co-ordinated multidisciplinary approach.

A note of caution has to be sounded however. Given the emphasis on “at risk” situations and “crisis intervention”, and the severe lack of financial resources, it may well be that many dual sensory impaired people will not benefit significantly from this legislative change. It is likely that many, particularly those in the older age group, will be described as having “low dependency” needs and their carers will be expected to continue to provide help and support.

**Staff Training**

All agencies clearly need to assess the training needs of their various staff groups and develop a clear strategy. Training needs will vary, with some staff requiring basic introductory courses on sensory impairment and others who are carrying out assessments or undertaking more intensive work requiring more in-depth input. Basic training courses could include information to increase awareness and understanding of dual sensory impairment; knowledge of the help and services available; and access issues. Particular “at risk” staff groups could be identified such as those working with older people in residential establishments and those with learning difficulties. Also whenever training is provided on single sensory impairment, input on dual sensory impairment could be included.

Meeting the communication needs of dual sensory impaired people also has implications for staff training. Consideration would need to be given to which groups of staff required this input and the nature and level of skills that were needed. For example, training courses could include basic advice on communicating with people with some residual hearing and hearing, British Sign Language Stages 1, 2, or 3, other signing methods and so on.

Finally providing disability equality training and anti-ageist practice training could also improve dual sensory impaired people’s access to services by encouraging an understanding of discriminatory practices and attitudes; fostering practice which focuses on and challenges the social causes of disability; and developing an empowering approach to service provision. Such training could involve dual sensory impaired people themselves.

**Co-ordination and Collaboration**

This study has highlighted the need for consideration to be given to various ways of improving co-ordination and collaboration between departments and between agencies. A Senior Social Services Manager could have the specific responsibility for ensuring that co-ordinated and multidisciplinary service delivery takes place for dual sensory impaired people. Such a role is perhaps a particularly vital one in Leicestershire, where several agencies provide the Social Work and rehabilitation services to Deaf, hearing impaired and visually impaired people. This manager could be responsible for ensuring that a network of professionals with appropriate skills is developed and that initiatives are encouraged to promote a more co-ordinated service response for dual sensory impaired people.
For example, the establishment of a computerised data bank which all agencies could access could provide professionals with information on the roles of other workers and the resources and services that are available. This could also possibly be used as a service user data bank to improve multidisciplinary working. Systems of cross referral from the Eye Department to the Ear, Nose and Throat Department and vice versa could be developed when a second sensory impairment is identified; and joint clinics for dual sensory impaired people established such as those recently piloted by the Society for the Blind between the Hearing Services Centre and the Low Vision Service. New and improved systems could be developed to encourage and enable health care professionals to refer people on to social care agencies.

Access to Services

There are two key remaining issues that local health and social care agencies need to address in order to ensure dual sensory impaired people's access to general mainstream services. These include addressing their communication needs and environmental considerations.

Meeting dual sensory impaired people's communication needs could be partially addressed by providing staff training as outlined above; however it is suggested that agencies develop specific policies on meeting communication needs to underpin and guide improvements to current practice. This study also pointed to the need for one to one support for some dual sensory impaired people. “Human resources” therefore need to be provided to enable some dual sensory impaired people to gain access to services, for example Guide Communicators and interpreters, including interpreters for people from minority ethnic communities.

Improving dual sensory impaired people's access to information is another consideration. Dual sensory impaired people need information about the help and services that are available at key points in time, such as at the time of diagnosis and/or registration but they also need information to be easily available at other locations. The findings from this study would also point to the need to provide information in appropriate formats such as in large print, on tape, in BSL on video, in Braille, on a one-to-one basis, and in other languages. To ensure equality of opportunity in service delivery dual sensory impaired people need access to the full range of information available to sighted and hearing people.

Environmental changes are a further way to improve access to mainstream services for dual sensory impaired people. Examples include using colour contrast, installing loop systems, improving lighting levels, providing text telephones, using large print and tactile signs and so on. The carrying out of an access audit of services and facilities could serve to highlight the actions required to improve access for dual sensory impaired people.

The Development of Specialist Local Resources

It is argued that there is a need to develop some specific local resources and services for dual sensory impaired people. These include direct services, and consultancy and outreach work.
Direct services would include the provision of functional assessments and rehabilitation services. This has implications for staff training as this study has suggested that these are currently being carried out from a single sensory perspective. The issue of the provision of aids and equipment to dual sensory impaired people would also need to be considered including such issues as funding expensive items of equipment currently not provided, such as radio microphone systems. Direct services may also include the provision of personal assistance services such as a Guide Communicator Service; opportunities for personal development could take various formats including assertiveness, coping skills and confidence training groups, developing peer support networks such as a “buddy scheme”, encouraging self advocacy, developing small educational/activity classes, providing opportunities for voluntary work and so on; information for dual sensory impaired people and their carers on dual sensory impairment and the help and services that are available including advice on benefits; counselling, advice and support services for dual sensory impaired people; and training and advice on communication skills to service users and carers.

A local consultancy and outreach service on dual sensory impairment could provide information, advice and training on dual sensory impairment and related access issues to professionals in other agencies and public and private bodies. The service could also actively stimulate and promote new initiatives such as the development of new locally based volunteer visiting services to reduce the isolation of dual sensory impaired people.

The National Voluntary Agencies

The national voluntary agencies for sensory impaired people and the Department of Health also have a role to play in improving services to dual sensory impaired people. It is argued that the single sensory impairment agencies such as the RNIB and the RNID need to take on board the findings from this study which would suggest that dual sensory impaired people do not form a small distinct marginal group. Many of the people these agencies are providing services to or are advocating on behalf of are dual sensory impaired, and this needs to be reflected in their service provision and in their campaigning role. It is suggested that these agencies would benefit from considering the access issues for dual sensory impaired people raised in this study. For example, the RNID could produce information leaflets in large print, on tape and in Braille and the RNIB could produce information in BSL on video. It is also suggested that the campaigns developed by the national agencies need to reflect more accurately the lives and experiences of dual sensory impaired people. Material which talks of silence and darkness is inaccurate; and pathetic, disempowering images perpetuate unhelpful myths and stereotypes.

Information and training materials are needed which more accurately reflect the epidemiology of dual sensory impairment and the experience of dual sensory impaired people. More awareness raising information is particularly required with regard to older people. Another role for the national agencies could be to commission or actively carry out research on aids and equipment for dual sensory impaired people, and encourage companies which design equipment for single sensory impaired people to carry out design modifications to better meet the needs of people with a dual impairment.
Clearly the agencies need to continue to work co-operatively together to campaign on behalf of dual sensory impaired people and in this context the recent suggestion that a United Kingdom Coalition on Deafblindness be established is to be welcomed. The coalition has the potential to bring dual sensory impaired people, their carers and professionals working for voluntary and statutory agencies together in partnership. The coalition could clearly serve several functions including a campaigning role to advocate for the rights and needs of dual sensory impaired people to be met.

The Department of Health

There are several ways in which the Department of Health could take an active role in helping to improve services to dual sensory impaired people. Further research could be commissioned into the epidemiology of dual sensory impairment, which could include secondary analysis of the OPCS Disability Survey Data (1988). Guidance could be issued to local authorities and voluntary agencies on the development and improvement of services for dual sensory impaired people; and ring-fenced funding could be made available. Finally a review could be commissioned of the training needs of professionals working with both single sensory and dual sensory impaired people. Consideration could be given to the issue of providing support, information and training to the small but increasing number of specialist professionals working with dual sensory impaired people for local authorities and local voluntary agencies. Currently there is little training available; no established means to share knowledge and skills; and no clear routes to obtain information about the help and advice available.

However, the satisfaction of dual sensory impaired people's needs is not the responsibility of health and social care agencies, but of society in general. This study has highlighted the widespread negative attitudes towards and lack of understanding of the experience of dual sensory impaired people of all ages, and the consequent need to inform and educate the general public. It is argued that wider societal changes are required to give disabled people equal opportunities to participate on an equal basis with others. Enforceable anti-discrimination legislation, which will impact on a wide range of community services, create opportunities for employment and education, and challenge many ingrained attitudes and working practices is urgently needed, and could act as a catalyst for change.

"Such legislation would stand as firm guidelines as to what is, and more importantly what is not, acceptable behaviour. The whole context in which relations between able-bodied and disabled people take place would be altered at legal and social as well as personal levels." (Oliver, 1985).

In this context, Eurolink Age (1990) has developed a code of good practice in meeting the needs of disability and ageing, which argues for older disabled people's rights to equal opportunity, without discrimination, for access to employment, education and public facilities. Positive action to improve the current situation for dual sensory impaired people of all ages is required at many levels. Until this happens, their basic needs will remain unmet and many will continue to experience enforced isolation.


Department of Health, Health Notice/Local Authority Social Services Letter, November 1988a.


The Disabled Persons (Service, Consultation and Representation) Act, 1986.


Inter-regional committee of the regional associations for the blind (1972). Services for the deaf-blind. 24pp Mimeo.


The National Health Service and Community Care Act, 1990.


APPENDIX 1

OPCS DISABILITY SURVEY FUNCTIONAL SEVERITY SCALE
**SEEING**

| S1  | Cannot tell by the light where the windows are | 12.0 |
| S2  | Cannot see the shapes of furniture in a room | 11.0 |
| S3  | Cannot see well enough to recognise a friend if close to his face | 10.0 |
| S4  | Cannot see well enough to recognise a friend who is an arm’s length away | 8.0 |
| S5  | Cannot see well enough to read a newspaper headline | 5.5 |
| S6  | Cannot see well enough to read a large print book | 5.0 |
| S7  | Cannot see well enough to recognise a friend across the room | 4.5 |
| S8  | Cannot see well enough to recognise a friend across the road | 1.5 |
| S9  | Has difficulty seeing to read ordinary newspaper print | 0.5 |

**HEARING**

| H1  | Cannot hear sounds at all | 11.0 |
| H2  | Cannot follow a TV programme with the volume turned up | 8.5 |
| H3  | Has difficulty hearing someone talking in a loud voice in a quiet room | 6.0 |
| H4  | Cannot hear a doorbell, alarm clock or telephone | 5.5 |
| H5  | Cannot use the telephone | 4.0 |
| H6  | Cannot follow a TV programme at a volume others find acceptable | 2.0 |
| H7  | Difficulty hearing someone talking in a normal voice in a quiet room | 1.5 |
| H8  | Difficulty following a conversation against background noise | 0.5 |
APPENDIX 2

THE SCREENING SHEET
Screening Sheet for an Individual with BOTH Poor Vision and Hearing Difficulties

PLEASE COMPLETE ALL SECTIONS ON BOTH SIDES OF THE FORM

<table>
<thead>
<tr>
<th>Your Name: __________________________</th>
<th>Job Title: __________________________</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agency and Address: __________________</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Telephone No: ________________________</td>
<td>Date: ______________________________</td>
</tr>
</tbody>
</table>

Name of Individual: __________________
Address: ____________________________

First 3 Letters of Surname

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
</table>

Date of Birth  dd mm yy  Age

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
</table>

Gender

- Male
- Female

Ethnic Group

- 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

(e.g. residential home, nursing home, group home, etc.)

Yes
No
Not known

Learning Difficulties

- Has learning difficulties (previously known as mental handicap)
- Yes
- No
- Not known

PLEASE TURN OVER
### Visual Difficulties (TICK 1 BOX ONLY)
(Please tick if in your opinion, the individual ...)

<table>
<thead>
<tr>
<th>Description</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>For example: cannot see well enough to recognise a friend who is an arm's length away.</td>
<td>Has severe visual difficulties (or is registered blind)</td>
</tr>
<tr>
<td>For example: cannot see well enough to recognise a friend across a room.</td>
<td>Has moderate visual difficulties (or is registered partially sighted)</td>
</tr>
<tr>
<td>For example: some individuals who have severe learning difficulties or who have experienced strokes etc.</td>
<td>Uncertain but &quot;Acts as if&quot; having visual difficulties</td>
</tr>
</tbody>
</table>

### Hearing Difficulties (TICK 1 BOX ONLY)
(Please tick if in your opinion the individual ...)

<table>
<thead>
<tr>
<th>Description</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>For example: has difficulty hearing someone talking in a loud voice in a quiet room, even if wearing a hearing aid.</td>
<td>Has profound/severe hearing difficulties (or is registered deaf with/without speech)</td>
</tr>
<tr>
<td>For example: with or without aids, has difficulty hearing someone talking in a normal voice in a quiet room.</td>
<td>Has moderate hearing difficulties (or is registered hard of hearing)</td>
</tr>
<tr>
<td>For example: some individuals who have severe learning difficulties or who have experienced strokes etc.</td>
<td>Uncertain but &quot;Acts as if&quot; having hearing difficulties</td>
</tr>
</tbody>
</table>

**Hearing Aid**
- Wears a hearing aid
  - Yes
  - No
  - Not known

**Speech Difficulties**
- Has speech difficulties or no speech
  - Yes
  - No
  - Not known

**Communication**
- Communicates by sign language or the use of hands e.g. BSL, Makaton, home made signs etc.
  - Yes
  - No
  - Not known

**If yes, please specify**

**Time of Onset**
- Born with visual difficulties
  - Yes
  - No
  - Not known
- Born with hearing difficulties
  - Yes
  - No
  - Not known

---

**Please return ALL sheets to:** Beryl Palmer, Leics Society for the Blind, Resources Centre, Gadding Road, Leicester LE5 5DU. Telephone 0533 490999

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To be Completed by the Project Worker
- Registered Blind
- Partially sighted
- Deaf without speech
- Deaf with speech
- Hard of hearing
APPENDIX 3

THE GUIDANCE LEAFLET USED
Project to Identify the Numbers and Needs of Individuals living in Leicestershire who have BOTH POOR VISION AND HEARING DIFFICULTIES

BACKGROUND

People who have a combined visual and hearing impairment are amongst the least understood and poorly provided for of all disabled people. Recent national reports* have highlighted the neglect of these individuals and the failure of service providers to acknowledge their existence and meet their needs.

A positive response to the recommendations of these reports has been made in Leicestershire by:-

The employment of a project worker

The setting up of a multi agency Planning Group by Social Services specifically concerned with the development of services for dual sensory impaired people

THE AIMS OF THE PROJECT

There are 3 main items:-

1) To identify as many individuals as possible, living in Leicestershire who have a COMBINED VISUAL AND HEARING IMPAIRMENT RESULTING IN COMMUNICATION DIFFICULTIES AND DAILY LIVING PROBLEMS.

2) To collect information about the characteristics and needs of a representative sample of these individuals and their carers.

3) To make recommendations about the provision of services to dual sensory impaired people and their carers.

The project will provide essential information for the planning and development of services.

The Project Worker is assisted in her task by a multi-agency Support Group comprising of representatives from the key main agencies, the Social Services Department, the Centre for Deaf People, the Health Authority, the Education Department and the National Deaf-Blind League.

COMPLETING THE SCREENING SHEET

Could you please complete the screening sheets for all individuals known to you who have BOTH POOR VISION AND HEARING DIFFICULTIES This includes:-

- children, adults, many OLDER PEOPLE and those with additional LEARNING DIFFICULTIES

- those whose hearing and vision is difficult to assess but who function or "act as if" they are hearing and vision impaired

- individuals who MAY NOT be registered blind, hard of hearing etc.

The sheet is extremely quick and easy to complete (2-5 minutes)

If possible please return ALL sheets both complete and incomplete within 3 weeks. (A pre-paid envelope is provided)

If you do not know anyone who has BOTH VISION and HEARING DIFFICULTIES please return all forms with the accompanying slip.

PLEASE SUPPORT THE PROJECT - YOUR COOPERATION IS VITAL IF WE ARE TO IMPROVE THE SITUATION FOR DUAL SENSORY IMPAIRED PEOPLE

CONFIDENTIALITY
The project has the full support and backing of the Social Services Department.

The information given will be treated as STRICTLY CONFIDENTIAL.

At a later stage in the project a small sample of hearing-vision impaired people will be interviewed. An approach will then be made through your agency to seek the agreement of any individual concerned to participate in a face to face interview.

FURTHER INFORMATION

Information and advice about local or national resources for dual sensory impaired people can be obtained by contacting the Project Worker

Beryl Palmer Leicestershire Society for the Blind Resource Centre, Gedding Road Leicester, LE5 5DU

Telephone: 0533 490909

* Breaking Through (1988) by the Deaf-Blind Services Liaison Group
* Signposts (1990) by the Social Services Inspectorate, Dept of Health
APPENDIX 4

THE FACT SHEETS USED TO RAISE PROFESSIONALS’ AWARENESS DURING THE IDENTIFICATION STAGE OF THE PROJECT
A) SENSORY IMPAIRMENT AND LEARNING DISABILITY

People with learning disabilities are more likely to have sensory impairments.

At least 1 in 3 adults with a learning disability also has a sensory impairment.

By the year 2000 this figure is likely to be 2 in 3.

Hearing and visual impairments are often undiagnosed and untreated.

Severity varies, but any loss of vision or hearing has a significant effect on the function of an individual who has fewer resources to compensate.

It is impossible for learning disabled people to reach their full potential unless their sensory impairments have been specifically addressed.

SOME POSSIBLE BEHAVIOURAL INDICATORS OF HEARING AND VISUAL IMPAIRMENTS

Many multi-disabled people are described as having disturbed or challenging behaviour. Some are inappropriately prescribed medication.

Examples include:

- Extreme frustration and aggression
- Extreme passivity
- Withdrawal
- Self-injurious/self-stimulating behaviour
- Obsessional behaviours and mannerisms

VISION IMPAIRMENTS

Examples include:

- Rocking
- Eye poking
- Light gazing or finger play
- Dislike of physical contact
- Dislike of moving in unfamiliar places
- Prefers bare feet/body
- Head held at an odd angle when performing tasks
- Shuffles feet when walking
- Examines items by touch or taste rather than sight
- Is startled when approached from certain directions.

HEARING IMPAIRMENTS

Examples include:

- Short attention span
- Isolates self from others - sits alone
- Is unable to "see" in a noisy environment
- Responds to some sounds and voices and not others
- Confuses names - linked to difficulty in understanding speech
- Misinterprets what is said
- Turns the volume of the Radio/TV up

* A Sense of Worth by Diana Harries, 1991. Copies available from Action for Blind People, 14/16 Verney Road, London, SW16 3DZ. Tel No.071 732 8771
B) IDENTIFYING HEARING AND VISION PROBLEMS AMONG OLDER PEOPLE

Older people are more likely to develop both hearing and vision problems.

Their hearing and vision losses may develop very gradually and go unrecognised.

The warning signs of their visual and hearing impairment may be misunderstood or ignored by both older people themselves, and the people around them. Problems created by sensory losses may be blamed on "senility" or labelled as confusion.

People who develop both impairments experience difficulties in communication and undertaking everyday tasks. They may become increasingly withdrawn, depressed and isolated.

Everyone experiences age related vision and hearing changes. How serious these problems become depends in part on how soon they are identified and whether appropriate resources are located for rehabilitation.

NEVER ACCEPT VISION AND HEARING LOSSES AS A "NORMAL" PART OF AGEING.

ALWAYS RULE OUT SENSORY PROBLEMS BEFORE ASSUMING A "MENTAL" PROBLEM.

IDENTIFY IMPAIRMENTS AS EARLY AS POSSIBLE AND REFER ON FOR MEDICAL ASSESSMENTS AND REHABILITATION.

Behavioural Signs of Vision Loss

1) Changes in reading habits e.g. holding material close to the face or at an odd angle, insisting on more light. Reading less.

2) Sitting unusually close to the TV.

3) Changes in the ability to adjust from dark to light such as going outside into bright sunlight. An increase in discomfort as a result of glare.

4) Changes in the ability to recognise familiar faces or to distinguish changes in the appearance of family or friends.

5) Changes in orientation or increased confusion, especially in unfamiliar areas, hesitance in movement, stumbling, bumping into things (i.e. people or furniture) and fumbling for door knobs. May be reluctant to go to unfamiliar places outside the immediate environment.

6) Changes in the ability to locate or recognise small objects such as glasses, keys etc. May grope for objects, misjudge distances between objects or touch objects in an uncertain way.

7) Changes in eating habits and table manners such as spilling food, knocking over cups or glasses and lowering the face close to the plate.

8) Changes in grooming habits, such as stains on clothes, mismatched clothes etc.

9) Decreased ability to discern colours particularly blues and greens.

Behavioural Signs of Hearing Loss

1) Changes in the volume of the TV or radio. Sitting closer than usual.

2) Sitting forward when spoken to. Intense face and/or lip watching. Turning an ear towards the speaker. Cupping a hand over the ear.

3) Changes in the ability to follow conversations such as inappropriate responses to questions or comments unrelated to the general discussion.

4) Says "eh" or equivalent in response to questions. Accuses others of mumbling. Repeatedly requests others to speak louder or more slowly.

5) Obviously responds better to raised voice (don't shout).
6) Only seems to understand when watching the lips of the person speaking.

7) Repeats the words of the speaker to verify what was heard was correct.

8) Talks too much (monopolises the conversation). Talks loudly - has difficulty monitoring his/her voice level.

9) Has difficulty in hearing conversations in noisy environments such as a dining room or a social gathering. May be reluctant to go to noisy places.

10) Changes in the ability to hear high pitched sounds such as women's voices or door bells; ignoring auditory warnings such as car horns or a ringing phone.

11) Inability to locate the source of the sound such as who is speaking in a group.

12) Withdrawal from places or situations where conversation is required or expected.

Acknowledgements are gratefully extended to both Rosie Hayes (1990) and Martha Bagley (1989), whose work was heavily drawn on in the development of these materials.
APPENDIX 5

THE LETTER WHICH ACCOMPANIED THE SCREENING SHEETS
Dear

Re Project to Identify the Numbers and Needs of Individuals who have BOTH Poor Vision and Hearing Difficulties living in Leicestershire

Recent national reports have highlighted the neglect of people who have a combined hearing and visual impairment and the failure of service providers to acknowledge their existence and meet their needs.

A positive response to improve this situation has been made in Leicestershire by the creation of the above project, which has the full support and backing of Brian Waller, the Director of Social Services; and by the setting up of a multi agency planning group by the Social Services Department specifically to address the needs of dual sensory disabled people.

It is essential for planning purposes that basic information is gathered about the numbers of people who have both poor vision and hearing difficulties. It is for this reason that we are seeking co-operation from you and your staff in the completion of simple screening sheets on individuals known to you. (This includes people whose vision and hearing is difficult to assess, for example those who have severe learning difficulties/intellectual impairment but who function or "act as if" they are hearing and vision impaired).

The screening sheets are extremely quick and easy to complete - it is a question of ticking a few boxes. Guidance is given on the form and in the accompanying leaflet. A fact sheet about sensory impairments is also included for your information. It would be appreciated if you could complete the attached slip and return all forms in the prepaid envelope by 13th December 1991 (please note that it is very important that you complete and return this slip even if you do not know of any individuals with BOTH poor vision and hearing difficulties).

If you require any more screening sheets or further information please do not hesitate to contact me. I realise that you are extremely busy and this is a further demand upon your time and would like to thank you in advance for your co-operation.

Yours sincerely

BERYL PALMER
PROJECT WORKER WITH HEARING-VISION IMPAIRED PEOPLE
APPENDIX 6

LETTER TO PRINCIPAL OFFICERS DISABLED PERSONS
22nd July 1991

Re: Project to Identify Hearing - Vision Impaired People Living in Leicestershire

Full support was given to the above project by the Divisional Management team last month. It was agreed that I should proceed by liaising with the Principal Assistants for Disabled Persons in each Division.

I have therefore enclosed for your information:-

- An Outline of the Project
- A copy of the Screening Sheet
- A Guidance Leaflet
- A fact sheet on Identifying Vision and Hearing Impairments Among Older People
  (A similar one is in the process of being written on identifying sensory impairments among people who have learning difficulties).

My aim is to approach professionals who are likely to be in contact with hearing-vision impaired people. It is hoped that the project will not only lead to the identification of a hitherto neglected group of people but also help to raise the awareness of professionals about sensory impairments.

The Registration Department of Social Services have offered to assist me in mailing out screening sheets to all local authority voluntary and private residential establishments. As regards the community I would like to approach the following groups of professionals:-

Social Workers with Visually Impaired People
Social Workers with Older People
Social Workers with People with Learning Difficulties
(and/or the multidisciplinary teams they may work with)

Occupational Therapists,
Home Care Organisers
Social Workers with Mentally Ill (and/or the multidisciplinary team they may work with)

Day Centres - Older People
- Physical Disability
- Learning Difficulties
- Mental Health

Any day facilities for children with disabilities
(Any other relevant professionals or establishments in your Division).

Obviously some of these professionals are more likely to...
have contact with sensory disabled people than others. I can approach these workers, either in person, by giving a short presentation at team meetings, or by letter, as appropriate.

A pilot study was undertaken in North West Leicestershire earlier this year. Jane James advised senior staff of the project at staff meetings and circulated a brief memo (a copy of which is attached). Jane then informed me of the names of relevant senior staff and left it for me to contact them. This system worked extremely well. It would seem sensible to repeat this system across the county, but it may be that you would prefer a different method.

I am anxious to proceed with the project as quickly as possible and would be grateful if you could advise your staff and contact me with relevant names etc by the end of July.

If you would like any further information or have any queries re the above please do not hesitate to contact me.

Thank you very much for your attention in this matter.

Yours sincerely,

Beryl Palmer
Project Worker
APPENDIX 7

PUBLICITY POSTER
DO YOU HAVE BOTH HEARING DIFFICULTIES (DEAF/HARD OF HEARING) AND POOR VISION (BLIND/PARTIAL SIGHT) DO YOU KNOW SOMEONE WHO HAS?

A Project has been set up which aims to improve services to these people. But first we need YOUR HELP in identifying the number of children, adults, older people living in Leicestershire who have BOTH POOR VISION AND HEARING DIFFICULTIES.

If you or someone you know (friend/family member) meets this description please contact before 31st March 1992 :-

Beryl Palmer or Jane Pridmore
Leicestershire Society for the Blind
Resource Centre
Gedding Road
Leicester
LE5 5DU

Telephone No: 0533 490909

PLEASE HELP US TO HELP YOU
APPENDIX 8

THE REMINDER LETTER
Dear

Re: Project to Identify the Numbers and Needs of Individuals who have BOTH Poor Vision and Hearing Difficulties Living in Leicestershire

On the 20th of November 1991 I wrote to advise you about the above project and to request your co-operation in the completion of screening sheets on individuals with both poor vision and hearing difficulties known to your establishment.

As I have not yet heard from you I am taking the liberty of writing to you again with further copies of the screening sheets and an information leaflet about the project.

The screening sheets are extremely quick and easy to complete - it is a question of ticking a few boxes. Guidance is given on the form and in the accompanying leaflet. Some establishments have found the completion of these forms to be a useful exercise for key workers to undertake.

A multi agency Community Care planning group as been set up by the Social Services Department specifically to address the needs of dual sensory disabled people, with the objective of improving service provision to this hitherto neglected group. However no planning group can progress without basic information about the numbers and characteristics of the individuals it is aiming to help. Your contribution is therefore of vital importance.

It would be appreciated if you could complete the attached slip and return all forms in the prepaid envelope by 16th November. (Please note that it is very important that you complete and return this slip even if you do not know of any individuals with BOTH poor vision and hearing difficulties).

If you require any more screening sheets or further information please do not hesitate to contact me. I realise that you are extremely busy and this is a further demand upon your time and would like to thank you in advance for your co-operation.

Yours sincerely,

BERYL PALMER
PROJECT WORKER WITH HEARING-VISION IMPAIRED PEOPLE

A Company Limited by Guarantee Registered in England No. 1630999 Charity No. 218992
APPENDIX 9

PROCEDURE FOR ADMINISTERING THE SCREENING SHEETS
Procedure for Personal Contact

A. Prior to Contact

1) Check if professional has a code number. If not assign one.

2) Put details of contact/visit on monthly contact with professionals page.

B. At Time of Contact

1) Give talk and handouts. Include: Screening sheets, guidance leaflets, fact sheets, envelopes, none known slip.

2) Complete type of respondent sheet noting: Names of respondents, number of sheets given out, agreed date due for return. Stamp sheets.

C. After Contact

1) Note issues, points of note arising from contact.

2) Letter reminder, 6 weeks after initial visit.

D. Upon Return of Sheets

1) Check content of forms. If filled in correctly assign professional/agency codes and individual numbers. If filled in incorrectly/ gaps on form telephone to clarify.

2) Complete type of respondent/statistical return sheet.

3) File.

4) Check if already known - if so attach to other filed copy and ignore below.

5) Check Blind and Partial Sight registers. Complete relevant box on screening sheet. Place x in right hand corner.

6) Note area code and complete area code box on screening sheet. (If not on register check maps etc. for area code)

7) Check Deaf or Hard of Hearing Register. Complete relevant box on screening sheet. Place x in right hand corner.

8) File in alphabetical order.

9) If time of onset is not known - check person’s file.

10) If time of onset of hearing is not known place in Centre for Deaf People check file.

11) If now complete place in COMPLETE file.

Procedure for Postal Screening Sheets

1) Assign a code number.

2) Put details of letter sent out on monthly contact sheet.

3) Assign a number to each establishment on the list.

4) Place number on type of respondent list and details of number of sheets. Stamp date due for return on first screening sheet. (3 weeks allowed)

5) Assign a number for type of respondent e.g. EPH and personal number for that establishment on each form sent out.

6) Post out: Covering letter, none known sheet, screening sheets, fact sheets, guidance notes, envelope.
7) Continue as above upon return of sheets but omit completion of numbers on the sheets.
<table>
<thead>
<tr>
<th>Date</th>
<th>Area Code</th>
<th>Name of Respondent</th>
<th>No. of Sheets Given Out</th>
<th>Date Due for Return</th>
<th>Reminders 1/2</th>
<th>Date Returned</th>
<th>Nos Returned Uncompleted</th>
<th>Nos Returned Completed</th>
<th>NIL Response</th>
</tr>
</thead>
</table>
APPENDIX 10

DETAILED STATISTICS BY AGE GROUP: CHILDREN, ADULTS, AND OLDER PEOPLE
1. CHILDREN & YOUNG PEOPLE AGED 0 - 19 YEARS

Prevalence

The total number of dual sensory impaired people identified in this age group was sixty-one: this represents a prevalence of 26.6 per 100,000 in the population of Leicestershire in this age group.

Age Profile

<table>
<thead>
<tr>
<th>AGE</th>
<th>NUMBER</th>
<th>% OF GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 4</td>
<td>5</td>
<td>8.2</td>
</tr>
<tr>
<td>5 - 9</td>
<td>20</td>
<td>32.9</td>
</tr>
<tr>
<td>10 - 14</td>
<td>16</td>
<td>22.9</td>
</tr>
<tr>
<td>15 - 19</td>
<td>20</td>
<td>32.8</td>
</tr>
<tr>
<td>TOTALS</td>
<td>61</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 21. The number of dual sensory impaired people under twenty years identified, and as a proportion of the population, by age.

Gender

A slightly higher number of males were identified; thirty-four males vs. twenty-seven females.

Ethnicity

<table>
<thead>
<tr>
<th>ETHNICITY</th>
<th>NUMBER</th>
<th>% OF GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>WHITE</td>
<td>52</td>
<td>85.2</td>
</tr>
<tr>
<td>ASIAN</td>
<td>8</td>
<td>13.1</td>
</tr>
<tr>
<td>NOT REPORTED</td>
<td>1</td>
<td>1.6</td>
</tr>
<tr>
<td>TOTALS</td>
<td>61</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 22. The number of dual sensory impaired people under twenty years identified, and as a proportion of the population, by ethnic origin.

Although 2.6% of the total population identified was Asian, a much higher percentage (13.1%) of this age group were Asian.

Type of School Attended

<table>
<thead>
<tr>
<th>SCHOOL TYPE</th>
<th>NUMBER</th>
</tr>
</thead>
<tbody>
<tr>
<td>DEAF/BLIND UNIT</td>
<td>2</td>
</tr>
<tr>
<td>D/B FURTHER EDUCATION</td>
<td>3</td>
</tr>
<tr>
<td>SLD SCHOOL</td>
<td>32</td>
</tr>
<tr>
<td>FURTHER EDUCATION COLLEGE</td>
<td>4</td>
</tr>
<tr>
<td>PRIMARY</td>
<td>3</td>
</tr>
<tr>
<td>SCHOOL FOR DEAF</td>
<td>1</td>
</tr>
<tr>
<td>SCHOOL FOR DELICATE</td>
<td>1</td>
</tr>
<tr>
<td>CAULDWELL HALL SCHOOL</td>
<td>1</td>
</tr>
<tr>
<td>NOT REPORTED</td>
<td>14</td>
</tr>
<tr>
<td>TOTAL</td>
<td>61</td>
</tr>
</tbody>
</table>

Table 23. The number of dual sensory impaired people under twenty years identified by type of school.

Approximately 50% of the children and young people attended a school for children with severe learning difficulties. However in nearly a third of cases the school attended was not known.

Type of Accommodation

Four of the children/young people lived in a residential establishment.
Learning Difficulties

The majority (82%) were described as having learning difficulties.

Communication Difficulties

A. Wears a Hearing Aid

<table>
<thead>
<tr>
<th>HEARING AID WORN?</th>
<th>NUMBER</th>
<th>% OF GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>19</td>
<td>31.1</td>
</tr>
<tr>
<td>NO</td>
<td>28</td>
<td>45.9</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>12</td>
<td>19.7</td>
</tr>
<tr>
<td>NOT REPORTED</td>
<td>2</td>
<td>3.3</td>
</tr>
<tr>
<td>TOTAL</td>
<td>61</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 24. The number of dual sensory impaired people under twenty years identified, and as a proportion of the population, by hearing aid usage.

About one-third of the children/young people wore a hearing aid.

B. Has Speech Difficulties

<table>
<thead>
<tr>
<th>SPEECH DIFFICULTIES</th>
<th>NUMBER</th>
<th>% OF GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>40</td>
<td>65.6</td>
</tr>
<tr>
<td>NO</td>
<td>14</td>
<td>23.0</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>7</td>
<td>11.5</td>
</tr>
<tr>
<td>TOTAL</td>
<td>61</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 25. The number of dual sensory impaired people under twenty years identified, and as a proportion of the population, by presence of speech difficulties.

Almost two-thirds of the children/young people had speech difficulties.

C. Communicates by Sign Language or Using Signs

<table>
<thead>
<tr>
<th>USES SIGNS</th>
<th>NUMBER</th>
<th>% OF GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>8</td>
<td>13.1</td>
</tr>
<tr>
<td>NO</td>
<td>43</td>
<td>70.5</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>10</td>
<td>16.4</td>
</tr>
<tr>
<td>TOTAL</td>
<td>61</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 26. The number of dual sensory impaired people under twenty years identified, and as a proportion of the population, by use of signs or sign language.

Relatively few used manual communication methods.

Manual Communication Methods Used

<table>
<thead>
<tr>
<th>METHOD</th>
<th>NUMBER</th>
</tr>
</thead>
<tbody>
<tr>
<td>NOT REPORTED</td>
<td>4</td>
</tr>
<tr>
<td>GESTURES</td>
<td>2</td>
</tr>
<tr>
<td>BSL</td>
<td>1</td>
</tr>
<tr>
<td>BSL/DB MANUAL</td>
<td>1</td>
</tr>
<tr>
<td>TOTAL</td>
<td>8</td>
</tr>
</tbody>
</table>

Table 27. The number of dual sensory impaired people under twenty years identified by manual method of communication used.
The combination of vision and hearing difficulties

<table>
<thead>
<tr>
<th>VISUAL IMPAIRMENT</th>
<th>SEVERE</th>
<th>MODERATE</th>
<th>UNCERTAIN</th>
<th>NOT KNOWN</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>SEVERE</td>
<td>15</td>
<td>3</td>
<td>16</td>
<td>1</td>
<td>35 (57.4%)</td>
</tr>
<tr>
<td>MODERATE</td>
<td>5</td>
<td>8</td>
<td>3</td>
<td>1</td>
<td>17 (27.9%)</td>
</tr>
<tr>
<td>UNCERTAIN</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>-</td>
<td>6 (9.8%)</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>3</td>
<td>3 (4.9%)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>21 (34.5%)</td>
<td>13 (21.3%)</td>
<td>22 (36.1%)</td>
<td>5 (8.2%)</td>
<td>61 (100%)</td>
</tr>
</tbody>
</table>

Table 28. The number of dual sensory impaired people under twenty years identified, and as a proportion of the population, by severity of hearing and visual difficulties.

The percentage of children and young people described as having severe hearing difficulties is higher than for the rest of the population (34.4% vs. 24.6%). The percentage described as having "uncertain" hearing difficulties is almost twelve times that of the rest of the population (36.1% vs. 3.1%). The figure for "uncertain" visual difficulties is similar that for the rest of the population (9.8% vs. 7.3%).

Time of Onset

<table>
<thead>
<tr>
<th>VISUAL IMPAIRMENT</th>
<th>CONGENITAL</th>
<th>ADVENTITIOUS</th>
<th>NOT KNOWN</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>CONGENITAL</td>
<td>35</td>
<td>1</td>
<td>6</td>
<td>42 (70.0%)</td>
</tr>
<tr>
<td>ADVENTITIOUS</td>
<td>-</td>
<td>3</td>
<td>-</td>
<td>3 (5.0%)</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>-</td>
<td>1</td>
<td>13</td>
<td>15 (25.0%)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>36 (60.0%)</td>
<td>5 (8.4%)</td>
<td>19 (31.7%)</td>
<td>60 (100%)</td>
</tr>
</tbody>
</table>

Table 29. The number of dual sensory impaired people under twenty years identified, and as a proportion of the population, by time of onset of hearing and visual difficulties.

Although Unknown responses were high, over 50% of children and young people were known to have been born with a vision and hearing difficulty.

Registration

A. Visual Impairment

<table>
<thead>
<tr>
<th>REGISTERED AS</th>
<th>NUMBER</th>
<th>% OF GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>BLIND</td>
<td>32</td>
<td>52.5</td>
</tr>
<tr>
<td>PARTIALLY SIGHTED</td>
<td>1</td>
<td>1.6</td>
</tr>
<tr>
<td>NOT REGISTERED</td>
<td>28</td>
<td>54.1</td>
</tr>
<tr>
<td>TOTAL</td>
<td>61</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 30. The number of dual sensory impaired people under twenty years identified, and as a proportion of the population, by registration of visual impairment.

A very small number of children and young people were registered as partially sighted. Over half were not registered.
### B. Hearing Impairment

<table>
<thead>
<tr>
<th>REGISTERED AS</th>
<th>NUMBER</th>
<th>% OF GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>DEAF W/O SPEECH</td>
<td>2</td>
<td>3.3</td>
</tr>
<tr>
<td>DEAF WITH SPEECH</td>
<td>3</td>
<td>4.9</td>
</tr>
<tr>
<td>HARD OF HEARING</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>NOT REGISTERED</td>
<td>56</td>
<td>92.0</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>61</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 31. The number of dual sensory impaired people under twenty years identified, and as a proportion of the population, by registration of hearing impairment. The vast majority of hearing disabled children/young people identified were not registered (92%). None were registered as hard of hearing.
2. ADULTS AGED 20 - 64 YEARS

Prevalence

The total number of dual sensory impaired people identified in this age group was 160; this represents a prevalence of 31.5 per 100,000 in this age group in the population of Leicestershire.

Age Profile

<table>
<thead>
<tr>
<th>AGE</th>
<th>NUMBER</th>
<th>% OF GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 - 24</td>
<td>13</td>
<td>8.1</td>
</tr>
<tr>
<td>25 - 29</td>
<td>22</td>
<td>13.8</td>
</tr>
<tr>
<td>30 - 34</td>
<td>14</td>
<td>8.8</td>
</tr>
<tr>
<td>35 - 39</td>
<td>14</td>
<td>8.8</td>
</tr>
<tr>
<td>40 - 44</td>
<td>24</td>
<td>15.0</td>
</tr>
<tr>
<td>45 - 49</td>
<td>17</td>
<td>10.6</td>
</tr>
<tr>
<td>50 - 54</td>
<td>13</td>
<td>8.1</td>
</tr>
<tr>
<td>55 - 59</td>
<td>16</td>
<td>10.0</td>
</tr>
<tr>
<td>60 - 64</td>
<td>21</td>
<td>13.1</td>
</tr>
<tr>
<td>TOTAL</td>
<td>160</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 32. The number of dual sensory impaired people between twenty and sixty-four years identified, and as a proportion of the population, by age.

Gender

A slightly higher number of males were identified; eighty-eight vs. seventy-two females.

Ethnicity

<table>
<thead>
<tr>
<th>ETHNICITY</th>
<th>NUMBER</th>
<th>% OF GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>WHITE</td>
<td>150</td>
<td>93.8</td>
</tr>
<tr>
<td>ASIAN</td>
<td>8</td>
<td>5.0</td>
</tr>
<tr>
<td>BLACK CARIBBEAN</td>
<td>1</td>
<td>0.6</td>
</tr>
<tr>
<td>NOT REPORTED</td>
<td>1</td>
<td>0.6</td>
</tr>
<tr>
<td>TOTAL</td>
<td>160</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 33. The number of dual sensory impaired people between twenty and sixty-four years identified, and as a proportion of the population, by ethnic group.

Although 2.6% of the total population identified was Asian, a much higher percentage (5%) of this age group were Asian.

Education

Two adults attended a Specialist Further Education establishment for Deaf/blind people and one attended a Further Education College.

Type of Accommodation

A. Living Alone

Only three adults (less than 2%) were stated to be living alone. However, the residential status was not known in 18% of cases.

B. In Residential Care

Seventy-one people (44%) lived in a residential establishment.

Learning Difficulties

A total of 106 people had learning difficulties; this represents two-thirds of this group.
Communication Difficulties

A. Wears a Hearing Aid

<table>
<thead>
<tr>
<th>HEARING AID?</th>
<th>NUMBER</th>
<th>% OF GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>42</td>
<td>26.3</td>
</tr>
<tr>
<td>NO</td>
<td>82</td>
<td>51.3</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>36</td>
<td>23.6</td>
</tr>
<tr>
<td>TOTAL</td>
<td>160</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 34. The number of dual sensory impaired people between twenty and sixty-four years identified, and as a proportion of the population, by hearing aid usage. Fewer people in this age range used a hearing aid compared to the rest of the dual sensory impaired population (26.3% vs. 42.4%).

B. Has Speech Difficulties

<table>
<thead>
<tr>
<th>SPEECH DIFFICULTIES?</th>
<th>NUMBER</th>
<th>% OF GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>78</td>
<td>48.8</td>
</tr>
<tr>
<td>NO</td>
<td>53</td>
<td>33.1</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>29</td>
<td>18.1</td>
</tr>
<tr>
<td>TOTAL</td>
<td>160</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 35. The number of dual sensory impaired people between twenty and sixty-four years identified, and as a proportion of the population, by presence of speech difficulties. Approximately 50% of this sample had speech difficulties; this is a far higher percentage than for the rest of the dual sensory impaired population (48.8% vs. 6.7%).

C. Communicates by Signing or Signs

<table>
<thead>
<tr>
<th>USES SIGNS</th>
<th>NUMBER</th>
<th>% OF GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>22</td>
<td>13.8</td>
</tr>
<tr>
<td>NO</td>
<td>108</td>
<td>67.5</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>30</td>
<td>18.8</td>
</tr>
<tr>
<td>TOTAL</td>
<td>160</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 36. The number of dual sensory impaired people between twenty and sixty-four years identified, and as a proportion of the population, by use of signs or sign language. More people in this age range communicated using sign language or signs than other dual sensory impaired people (13.8% vs. 2.0%).

Manual Communication Method Used

<table>
<thead>
<tr>
<th>METHOD</th>
<th>NUMBER</th>
</tr>
</thead>
<tbody>
<tr>
<td>DEAF/BLIND MANUAL</td>
<td>2</td>
</tr>
<tr>
<td>BRITISH SIGN LANGUAGE</td>
<td>1</td>
</tr>
<tr>
<td>BSL/GESTURES</td>
<td>2</td>
</tr>
<tr>
<td>MAKATON</td>
<td>4</td>
</tr>
<tr>
<td>GESTURES</td>
<td>6</td>
</tr>
<tr>
<td>TOTAL</td>
<td>15</td>
</tr>
</tbody>
</table>

Table 37. The number of dual sensory impaired people between twenty and sixty-four years identified by manual communication method used.
The combination of vision and hearing difficulties

<table>
<thead>
<tr>
<th>VISUAL IMPAIRMENT</th>
<th>SEVERE</th>
<th>MODERATE</th>
<th>UNCERTAIN</th>
<th>NOT KNOWN</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>SEVERE</td>
<td>22</td>
<td>39</td>
<td>14</td>
<td>4</td>
<td>79 (49.4%)</td>
</tr>
<tr>
<td>MODERATE</td>
<td>14</td>
<td>38</td>
<td>11</td>
<td>2</td>
<td>65 (40.6%)</td>
</tr>
<tr>
<td>UNCERTAIN</td>
<td>4</td>
<td>4</td>
<td>6</td>
<td>-</td>
<td>14 (8.0%)</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>2 (1.3%)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>41 (25.6%)</td>
<td>81 (50.6%)</td>
<td>31 (19.4%)</td>
<td>7 (4.4%)</td>
<td>160 (100%)</td>
</tr>
</tbody>
</table>

Table 38. The number of dual sensory impaired people between twenty and sixty-four years identified, and as a proportion of the population, by severity of visual and hearing difficulties.

The percentage of adults described as having "uncertain" vision and/or hearing difficulties is higher than for the rest of the population. (Vision 8.8% vs. 5.9%; Hearing 19.4% vs. 4.0%)

Time of Onset

<table>
<thead>
<tr>
<th>HEARING IMPAIRMENT</th>
<th>CONGENITAL</th>
<th>ADVENTITIOUS</th>
<th>NOT KNOWN</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>CONGENITAL</td>
<td>17</td>
<td>6</td>
<td>6</td>
<td>29 (18.1%)</td>
</tr>
<tr>
<td>ADVENTITIOUS</td>
<td>7</td>
<td>21</td>
<td>5</td>
<td>33 (20.6%)</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>10</td>
<td>4</td>
<td>84</td>
<td>98 (61.3%)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>35 (21.3%)</td>
<td>31 (19.4%)</td>
<td>95 (59.4%)</td>
<td>160 (100%)</td>
</tr>
</tbody>
</table>

Table 39. The number of dual sensory impaired people between twenty and sixty-four years identified, and as a proportion of the population, by time of onset of visual and hearing difficulties.

Registration

A. Visual Impairment

| REGISTERED AS       | NUMBER | % OF GROUP | |
|---------------------|--------|------------| |
| BLIND               | 71     | 44.4       | |
| PARTIALLY SIGHTED   | 26     | 16.3       | |
| NOT REGISTERED      | 63     | 39.3       | |
| TOTAL               | 160    | 100        | |

Table 40. The number of dual sensory impaired people between twenty and sixty-four years identified, and as a proportion of the population, by registration of visual impairment.

The percentage of this group not registered as visually impaired is higher than for the rest of the population. (3.9% vs. 29.6%)

B. Hearing Impairment

| REGISTERED AS       | NUMBER | % OF GROUP | |
|---------------------|--------|------------| |
| DEAF W/O SPEECH     | 6      | 3.8        | |
| DEAF WITH SPEECH    | 6      | 3.8        | |
| HARD OF HEARING     | 18     | 11.3       | |
| NOT REGISTERED      | 130    | 81.1       | |
| TOTAL               | 160    | 100        | |

Table 41. The number of dual sensory impaired people between twenty and sixty-four years identified, and as a proportion of the population, by registration of hearing impairment.

There are far fewer adults registered as hard of hearing in comparison with the rest of the population (11.3% vs. 26.2%); and very high percentage of this group are not registered as hearing impaired at all.
3. OLDER PEOPLE AGED 65 YEARS AND OVER

Prevalence

A total of 1241 people were identified; this represents a prevalence of 962 per 100,000 of the population of Leicestershire in this age range.

Age Profile

<table>
<thead>
<tr>
<th>AGE</th>
<th>NUMBER</th>
<th>% OF GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>65 - 69</td>
<td>38</td>
<td>3.1</td>
</tr>
<tr>
<td>70 - 74</td>
<td>53</td>
<td>4.2</td>
</tr>
<tr>
<td>75 - 79</td>
<td>129</td>
<td>10.4</td>
</tr>
<tr>
<td>80 - 84</td>
<td>240</td>
<td>19.3</td>
</tr>
<tr>
<td>85 - 89</td>
<td>362</td>
<td>29.1</td>
</tr>
<tr>
<td>90 - 94</td>
<td>286</td>
<td>23.0</td>
</tr>
<tr>
<td>95 - 99</td>
<td>111</td>
<td>8.9</td>
</tr>
<tr>
<td>100 - 105</td>
<td>22</td>
<td>1.8</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1241</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 42. The number of dual sensory impaired people aged sixty-five years and over identified, and as a proportion of the population, by age.

Gender

Nearly three quarters of the older people identified were female; 885 females vs. 352 males, with 4 people whose gender was not known. It is clear that as age increases so does the percentage of females.

Ethnicity

<table>
<thead>
<tr>
<th>ETHNICITY</th>
<th>NUMBER</th>
<th>% OF GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>WHITE</td>
<td>1212</td>
<td>97.7</td>
</tr>
<tr>
<td>ASIAN</td>
<td>22</td>
<td>1.8</td>
</tr>
<tr>
<td>BLACK CARIBBEAN</td>
<td>2</td>
<td>0.2</td>
</tr>
<tr>
<td>BLACK OTHER</td>
<td>1</td>
<td>0.1</td>
</tr>
<tr>
<td>CHINESE</td>
<td>1</td>
<td>0.1</td>
</tr>
<tr>
<td>POLISH</td>
<td>1</td>
<td>0.1</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1241</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 43. The number of dual sensory impaired people aged sixty-five years and over identified, and as a proportion of the population, by ethnic origin. Less than two percent of the dual sensory impaired people identified in this age group were Asian.

Type of Accommodation

A. Living in Residential Care.

<table>
<thead>
<tr>
<th>IN CARE?</th>
<th>NUMBER</th>
<th>% OF GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>461</td>
<td>37.1</td>
</tr>
<tr>
<td>NO</td>
<td>734</td>
<td>59.1</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>46</td>
<td>3.7</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1241</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 44. The number of dual sensory impaired people aged sixty-five years and over identified, and as a proportion of the age group, by whether living in residential care.

Over one-third of these older people lived in residential establishments. This varied by age, however: eighteen (19.8%) people aged between 65 - 74 years lived in residential care, eighty-five (23%) people aged between 75 - 84 years lived in residential care, and 358, or 46% of people aged over 85 years lived in residential care.

B. Living Alone
Approximately one quarter of this age group lived alone. This was also true for older people aged 85 years and over, of whom 23.6% lived alone.

### Learning Difficulties

<table>
<thead>
<tr>
<th>LEARNING DIFFICULTIES?</th>
<th>NUMBER</th>
<th>% OF GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>15</td>
<td>1.2</td>
</tr>
<tr>
<td>NO</td>
<td>1194</td>
<td>96.2</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>32</td>
<td>2.6</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1241</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 46. The number of dual sensory impaired people aged sixty-five years and over identified, and as a proportion of the age group, by learning difficulties.

A very small percentage of older people had learning difficulties.

### Communication Difficulties

#### A. Wears a Hearing Aid

<table>
<thead>
<tr>
<th>WEARS HEARING AID?</th>
<th>NUMBER</th>
<th>% OF GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>532</td>
<td>42.9</td>
</tr>
<tr>
<td>NO</td>
<td>345</td>
<td>27.8</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>364</td>
<td>29.3</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1241</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 47. The number of dual sensory impaired people aged sixty-five years and over identified, and as a proportion of the age group, by hearing aid usage.

There was a higher percentage of hearing aids users amongst older people than amongst adults and children/young people. (42.9% vs. 31.1% for children and 26.3% for adults)

#### B. Has Speech Difficulties

<table>
<thead>
<tr>
<th>SPEECH DIFFICULTIES?</th>
<th>NUMBER</th>
<th>% OF GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>47</td>
<td>3.8</td>
</tr>
<tr>
<td>NO</td>
<td>925</td>
<td>74.5</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>269</td>
<td>21.7</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1241</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 48. The number of dual sensory impaired people aged sixty-five years and over identified, and as a proportion of the age group, by presence of speech difficulties A very much lower percentage of older people had speech difficulties compared to the rest of the population. (3.8% vs. 53.4%)
C. Communicates by Signing or Signs

<table>
<thead>
<tr>
<th>USES SIGNS</th>
<th>NUMBER</th>
<th>% OF GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>18</td>
<td>1.5</td>
</tr>
<tr>
<td>NO</td>
<td>936</td>
<td>75.4</td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>289</td>
<td>23.1</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>1241</td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

Table 49. The number of dual sensory impaired people aged sixty-five years and over identified, and as a proportion of the age group, by use of signs or sign language.

A much smaller percentage of older people communicated by means of sign language or signs, as compared to children/young people and adults. However, just over one-third (37.5%) of all the dual sensory impaired people who used manual communication were over 65 years of age.

Manual Communication Method Used

<table>
<thead>
<tr>
<th>METHOD</th>
<th>NUMBER</th>
</tr>
</thead>
<tbody>
<tr>
<td>DEAF/BLIND MANUAL</td>
<td>5</td>
</tr>
<tr>
<td>D/B MANUAL/GESTURES</td>
<td>1</td>
</tr>
<tr>
<td>GESTURES</td>
<td>6</td>
</tr>
<tr>
<td>BRITISH SIGN LANGUAGE</td>
<td>1</td>
</tr>
<tr>
<td>BSL/GESTURES</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>14</strong></td>
</tr>
</tbody>
</table>

Table 50. The number of dual sensory impaired people aged sixty-five years and over identified, by manual communication methods used.

The combination of vision and hearing difficulties

<table>
<thead>
<tr>
<th>VISUAL IMPAIRMENT</th>
<th>HEARING IMPAIRMENT</th>
<th>SEVERE</th>
<th>MODERATE</th>
<th>UNCERTAIN</th>
<th>NOT KNOWN</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>SEVERE</td>
<td>183</td>
<td>414</td>
<td>31</td>
<td>32</td>
<td>660 (53.2%)</td>
<td></td>
</tr>
<tr>
<td>MODERATE</td>
<td>108</td>
<td>362</td>
<td>16</td>
<td>39</td>
<td>525 (42.3%)</td>
<td></td>
</tr>
<tr>
<td>UNCERTAIN</td>
<td>12</td>
<td>26</td>
<td>8</td>
<td>-</td>
<td>46 (3.7%)</td>
<td></td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>1</td>
<td>8</td>
<td>-</td>
<td>1</td>
<td>10 (0.8%)</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>304 (24.5%)</td>
<td>810 (65.3%)</td>
<td>55 (4.4%)</td>
<td>72 (5.8%)</td>
<td>1241 (100%)</td>
<td></td>
</tr>
</tbody>
</table>

Table 51. The number of dual sensory impaired people aged sixty-five years and over identified, and as a proportion of the age group, by severity of visual and hearing difficulties.

Of the total population of dual sensory impaired people with severe/severe combined vision and hearing difficulties, 83% were aged 65 years and over. Fifty percent of the total dual sensory impaired population with "uncertain" hearing difficulties were aged over 65 years; and 70% of the total population of people with "uncertain" visual difficulties were aged over 65 years.

Time of Onset

<table>
<thead>
<tr>
<th>VISUAL IMPAIRMENT</th>
<th>HEARING IMPAIRMENT</th>
<th>CONGENITAL</th>
<th>ADVENTITIOUS</th>
<th>NOT KNOWN</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>CONGENITAL</td>
<td>9</td>
<td>13</td>
<td>4</td>
<td>26 (2.2%)</td>
<td></td>
</tr>
<tr>
<td>ADVENTITIOUS</td>
<td>4</td>
<td>694</td>
<td>29</td>
<td>727 (58.6%)</td>
<td></td>
</tr>
<tr>
<td>NOT KNOWN</td>
<td>2</td>
<td>33</td>
<td>452</td>
<td>487 (39.2%)</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>15 (1.2%)</td>
<td>740 (59.7%)</td>
<td>485 (39.1%)</td>
<td>1240 (100%)</td>
<td></td>
</tr>
</tbody>
</table>

Table 52. The number of dual sensory impaired people aged sixty-five years and over identified, and as a proportion of the age group, by time of onset of visual and hearing difficulties.

Only a small number of older people were known to have been born with vision and hearing difficulties, although there were a high proportion of Not Known responses to this question. One observation is missing from this Table.
Registration

A. Visual Impairment

<table>
<thead>
<tr>
<th>REGISTERED AS</th>
<th>NUMBER</th>
<th>% OF GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>BLIND</td>
<td>594</td>
<td>47.9</td>
</tr>
<tr>
<td>PARTIALLY SIGHTED</td>
<td>289</td>
<td>23.3</td>
</tr>
<tr>
<td>NOT REGISTERED</td>
<td>358</td>
<td>28.8</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1241</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 53. The number of dual sensory impaired people aged sixty-five years and over identified, and as a proportion of the age group, by registration of visual impairment.

Most of those registered as blind or partially sighted were in this age group (883 vs. 130 in all other age groups).

B. Hearing Impairment

<table>
<thead>
<tr>
<th>REGISTERED AS</th>
<th>NUMBER</th>
<th>% OF GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>DEAF W/O SPEECH</td>
<td>3</td>
<td>0.2</td>
</tr>
<tr>
<td>DEAF WITH SPEECH</td>
<td>7</td>
<td>0.6</td>
</tr>
<tr>
<td>HARD OF HEARING</td>
<td>341</td>
<td>27.5</td>
</tr>
<tr>
<td>NOT REGISTERED</td>
<td>890</td>
<td>71.7</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1241</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 54. The number of dual sensory impaired people aged sixty-five years and over identified, and as a proportion of the age group, by registration of hearing impairment.

Almost all the people registered as hard of hearing were in this age group. (341 vs. 18 in all other age groups).
APPENDIX 11

SOURCES OF STATISTICAL INFORMATION
Three main sources were used; professionals working in the community and residential establishments, and the existing registers of people with vision and hearing difficulties. In addition, an advertising campaign resulted in some self-referrals.

1. PROFESSIONALS WORKING IN THE COMMUNITY

A. Key Voluntary Agencies

Centre for Deaf People

Six Social Workers/Rehabilitation Workers identified 95 people. The mean number identified was 16, with a range of 1 to 16.

Society for the Blind

Thirteen Rehabilitation Workers/Development Workers identified 233 people; the mean number was 16, with a range between 2 and 44. An additional 97 people were identified by other staff, with the total identified by the Society for the Blind staff being 330.

B. Social Services

Social Workers with Visually Impaired People

Fifteen Social Workers identified 347 people; the mean number identified was 23, with a range between 2 and 72.

Social Workers with Older People/Generic Social Workers

The response was poor. The total number identified by five workers was 8, with a range between 1 and 3.

Social Workers with Learning Disabled People/Generic Social Workers

The response rate was poor - approximately 50% replied to requests for information. The number identified by three workers was 10, with a range between 2 and 4.

Home Care Organisers

A response was received from 50% of all teams. The total number of dual sensory impaired people identified by four teams was 22; the mean number per team was 3, with a range between 2 and 12.
County-wide Health Division Social Workers

Only one member of staff from one hospital - the General Hospital - responded. This person identified 7 people.

C. The Health Authority

Community Nurses

All the units across the County responded and 29 people were identified. The mean per Team was 7, with range between 2 and 14.

Speech Therapists

No responses were received.

Hearing Therapists

The hearing therapists and technicians identified 16 people. Inspection of past hearing therapist records revealed a further 28 people.

Glenfield General Hospital

A nurse identified one person. Occupational Therapists identified a further 7 people.

Glenfield Unit (Learning Disabilities)

Staff in the Wards and Villas identified 22 people; the mean was 2 per ward/villa, with a range of 1 to 5.

A Community Nurse identified a further two people, making a total of twenty-four.

Mill Lodge, Kegworth

One person was identified.

The Towers Psychiatric Hospital

Three people were identified at this hospital. All were older people aged 65 years and over.

Day Care Facilities

Day Nurseries

An 86% response rate, but no children were identified.

Day Centres for Older People

A 91% response rate; the total number of people identified was 7, with only 0.6 per centre, and a range between 1 and 2.
Day Centre for People with Learning Disabilities

There was a 100% response rate, with a total of 27 people identified. The mean was 3/centre, and the range was between 0 and 7.

Day Centres for People with a Physical Disability

A 75% response rate was achieved, but no dual sensory impaired people were identified.

Day Centres for People with Mental Health Problems

A 70% response rate identified only 1 person.

D. Education Department

The Principal of the Service for Visually Impaired Children identified 30 children/young people.
The Principal of the Service for Hearing Impaired Children identified 4 children/young people.

E. Other Voluntary Agencies

Age Concern (City) identified 7 people.
Age Concern (County) identified 2 people.
Leicester Quaker Housing Association identified 3 people.

There was no response from the Red Cross, Mencap, WRVS, The Guild of the Disabled and all other smaller voluntary agencies approached.

2. PROFESSIONALS WORKING IN RESIDENTIAL ESTABLISHMENTS

F. Social Services

Homes for Older People

A 98% response rate was achieved; a total number of people identified was 146. The mean was 3.4 per home, with a range between 0 and 12.

Homes for People with Learning Disabilities

A 100% response rate identified a total of 7 people; the mean was 0.8 persons per home, with range between 0 and 2.

G. The Independent Sector

Voluntary/Private Homes for Older People

A 97% response rate identified a total of 161 people; the mean number per home was 1.3, with a range between 0 and 16.

Non Elderly Private/Voluntary Homes

A 93% response rate was achieved. The total number of people identified was 24, with a mean of 0.4 people per home, and a range between 0 and 4.
Registered Nursing Homes

An 88% response rate identified a total of 67 people. The mean number per home was 1.6, with a range between 0 and 3.

3. USE OF EXISTING REGISTERS

Registers of visual and hearing impairments are quite separate. Although the blind and partial sight registers contain limited information about hearing impairment, the deaf and hard of hearing registers do not refer to visual impairment.

Accordingly, two methods were used to identify dual sensory impaired people. First, a cross-referencing of names was undertaken between the registers; and second, the visual impairment registers were trawled for people with additional hearing difficulties. This information was obtained from a variety of sources, since no systematic recording of hearing status is undertaken. The sources used included BD8 details, and a previous survey undertaken by the Society for the Blind some years ago.

H. Cross Referencing of Blind and Partial Sight Register with Deaf with/without Speech and Hard of Hearing Registers

<table>
<thead>
<tr>
<th>VISUAL IMPAIRMENT</th>
<th>DEAF W/O SPEECH</th>
<th>DEAF WITH SPEECH</th>
<th>HARD OF HEARING</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>BLIND</td>
<td>5</td>
<td>7</td>
<td>202</td>
<td>214</td>
</tr>
<tr>
<td>PARTIALLY SIGHTED</td>
<td>2</td>
<td>7</td>
<td>87</td>
<td>96</td>
</tr>
<tr>
<td>TOTAL</td>
<td>7</td>
<td>14</td>
<td>289</td>
<td>310</td>
</tr>
</tbody>
</table>

Table 55. The number of dual sensory impaired people identified by cross referencing the Blind and Partial Sight registers with the Deaf with/without Speech and Hard of Hearing registers.

I. People registered as Blind or Partially Sighted recorded as having a hearing impairment

The total number of people on the visual impairment registers who were also recorded as having a hearing impairment was 277; of these, only 104, or 38% were subsequently found to have this additional impairment registered.

The way the hearing impairment details were recorded showed a lack of understanding of categories of deafness, and the 62% who were not registered would be most unlikely to have had contact with the Centre for Deaf People.

J. Mental Handicap Register

The Leicestershire Health Authority were compiling a Mental Handicap Register whilst this current study was being undertaken. They had interviewed 1605 people with learning difficulties, and a draft version of the register was inspected. Only 33 of the people on it were identified as having vision and hearing difficulties. This seems to be a very low figure, given that current research suggests that more than one-third of people with learning disabilities have at least one sensory impairment.

K. Sense Data Base

A total of 13 people living in Leicestershire were identified.

4. SELF-REFERRAL

Referral by self, a family member or friend in response to advertising resulted in 25 dual sensory people being identified.

Referral by self/family/friend in response to advertising on County Sound, a tape magazine produced by the Society for the Blind identified an additional 14 people.
APPENDIX 12

THE INTERVIEW SCHEDULE
INTRODUCTION

I would like to ask you about the sorts of difficulties you experience in your daily life, how you cope with these and how you think they could be made easier or overcome. After this I would like you to tell me about your experience of using a variety of services, your satisfaction with these and how you feel they could be improved.

I will be meeting with approximately 23 disabled people similar to yourself and covering the same issues with them. The information I collect will form part of a report which aims to increase understanding of the experience and needs of people who have both poor vision and hearing difficulties or who are deafblind and to recommend improvements to services.

The interview with you is in strictest confidence. Your name will not be revealed.

I would like to tape record the interview so that I have a record of what you say to me.

Clarify best method of communication. Any special considerations, need for loop system etc.

If you do not hear me properly at any point in the interview please stop me and ask me to repeat what I have said.

1. Introduction

Nature of impairments (Vision, hearing, other) ? Time of onset (nature - traumatic, slow etc.) ? If childhood onset educational experiences.

2. Difficulties experienced in daily life

Sorts of difficulties experienced in daily life, how these are coped with, how they could be made easier or be overcome?

Communication

How (sign language, lip-reading, etc.) ? Difficult situations (groups, streets etc.)? Communication with friends? Communication with strangers? Telephone? Written?

What could be done to help/improve/overcome.............?

Information

Print, large print, Braille? Radio/T.V.? What is going on around you - local/further afield?

What could be done to help/improve/overcome..................?

Personal Care

Problems looking after self? Cleaning/cooking shopping/other?

(Probe: If receiving personal assistance - nature of help, satisfaction, choice and control, flexibility, suitable times, quality of interpersonal interaction etc.)

What could be done to help/improve/overcome....................?

Mobility

Getting about in own home? Getting about in local area? (Probe alone or accompanied?) Social events/visiting others?

What could be done to help/improve/overcome.....................?

Transport

Use of public transport? Improvements? Special transport schemes e.g. Dial-a-Ride? Comments?

What could be done to help/improve/overcome..............?
Employment (under 65 years)

Working at the moment? If yes: What job? Satisfaction? (Probe: support in workplace, attitudes of others, training received etc.)

If no: Worked in the past? Would like a job now? Assistance offered looking for work? (Probe: support in workplace, attitudes of others, training received etc.)

What could be done to help/improve/overcome?

Education

Attendance at any classes? If yes: Difficulties/improvements?

If no: Would you like to? What stops you from attending? (Probe: transport, communication, income etc.)

What could be done to help/improve/overcome?

Leisure Activities

Satisfaction with leisure time? Restrictions? (Probe: income, transport, communication etc.)

Specialist groups for disabled/older people?

What could be done to help/improve/overcome.................?

Social contacts Relationships with others?

Feelings about meeting friends/family/strangers. (Probe: behaviour, attitudes)

What could be done to help/improve/overcome?

Finance/Income

State benefits? Additional expenses related to disability? Feelings about financial situation? What could be done to help/improve/overcome?

Informal support

Who from? How? What ways?

Dependence/independence

Other concerns? (health, housing etc.)

What could be done to help/improve/overcome?

3. Experience/perceptions of services

I would now like to ask you about your experience of using a variety of services, how satisfied you are with them and how you feel they could be improved?

General community services (shops, banks etc.) (Probe: issues about use, access, etc.)

Health (GP, hospital clinics, visits )

Comments/improvements?

Use of hearing therapist/ low vision specialist?

Awareness/accessibility/acceptability?
Social Services (Social Worker, Day Centres, Home Carers, Welfare Rights, Meals on Wheels)
Contacts/comments/improvements?
Awareness/accessibility/acceptability?

Society for the Blind (Rehabilitation, social groups, information tapes, talking books/newspapers)
Contacts/comments/improvements?
Aids? Registration?
Awareness, accessibility, acceptability?

Centre for Deaf People (Social Workers, rehabilitation, groups, interpreters)
Contacts/comments/improvements?
Aids? Registration?
Information?
Service co-ordination?

Other services? (Age Concern etc.)

National Voluntary Agencies? (Sense, National Deafblind League, RNIB, RNID)

Date...

Demographic details
Name of respondent........................................
Gender............................................................
Ethnic Origin....................................................
Age...............................................................
Family............................................................
Household Composition....................................
Marital Status................................................
Type of Accommodation...................................
Occupation/Previous Occupation.....................
Cause of hearing impairment...........................
Cause of visual impairment............................
OPCS functional difficulties scale ....................
2nd interview YES/NO
FOR COMPLETION BY INTERVIEWER

1. Interview directly with person

Interview with some assistance.................................

Interview with BSL Interpreter .................................

Interview with Interpreter for Asian languages.............

Other...........................................................................

2. Area:-  City  Town  Village  Rural

3. Registration:-
   Blind  Partial Sight  Not Registered
   Deaf without speech  Deaf with Speech  Not Registered

4. Nature of communication

...................................................................................

...................................................................................

...................................................................................

5. Observations................................................................

...................................................................................
APPENDIX 13

PROFILE OF DUAL SENSORY IMPAIRED ADULTS AND OLDER PEOPLE
<table>
<thead>
<tr>
<th>NAME</th>
<th>DONNA PHILIPS</th>
<th>ANDREW DUNCAN</th>
<th>ALAN WOODGER</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGE</td>
<td>47</td>
<td>43</td>
<td>38</td>
</tr>
<tr>
<td>ETHNICITY</td>
<td>WHITE</td>
<td>WHITE</td>
<td>WHITE</td>
</tr>
<tr>
<td>TIME OF ONSET OF HEARING IMPAIRMENT</td>
<td>AT BIRTH</td>
<td>? FROM BIRTH DETERIORATION OVER YEARS FIRST HEARING AID AT 23 YEARS</td>
<td>AT BIRTH DETERIORATED SINCE</td>
</tr>
<tr>
<td>TIME OF ONSET OF VISUAL IMPAIRMENT</td>
<td>DETERIORATION OVER YEARS RECENT DIAGNOSIS</td>
<td>AT BIRTH DETERIORATED SINCE</td>
<td>AT BIRTH DETERIORATED SINCE</td>
</tr>
<tr>
<td>CHRONIC ILLNESSES/OTHER IMPAIRMENTS</td>
<td>WEAK LEFT LUNG</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SEVERITY OF VISUAL IMPAIRMENT</td>
<td>SEVERE</td>
<td>SEVERE</td>
<td>SEVERE</td>
</tr>
<tr>
<td>FUNCTIONAL SEVERITY OF VISUAL IMPAIRMENT</td>
<td>1.5</td>
<td>10.00</td>
<td>5.0</td>
</tr>
<tr>
<td>SEVERITY OF HEARING IMPAIRMENT</td>
<td>SEVERE</td>
<td>SEVERE</td>
<td>SEVERE</td>
</tr>
<tr>
<td>FUNCTIONAL SEVERITY OF HEARING IMPAIRMENT</td>
<td>8.5</td>
<td>6.0</td>
<td>8.5</td>
</tr>
<tr>
<td>REGISTRATION OF HEARING IMPAIRMENT</td>
<td>HARD OF HEARING, DATE UNKNOWN</td>
<td>HARD OF HEARING, 1991</td>
<td></td>
</tr>
<tr>
<td>LIVES WITH?</td>
<td>ALONE</td>
<td>ALONE, BUT MOTHER CLOSE</td>
<td>WIFE</td>
</tr>
<tr>
<td>HOUSING</td>
<td>RENTED FLAT</td>
<td>OWN HOME</td>
<td>OWN HOME</td>
</tr>
<tr>
<td>LOCATION</td>
<td>TOWN</td>
<td>RURAL</td>
<td>CITY</td>
</tr>
<tr>
<td>NAME</td>
<td>CHRISTINE BELL</td>
<td>RAM PANCHOLI</td>
<td>PAUL WARD</td>
</tr>
<tr>
<td>------------</td>
<td>----------------</td>
<td>--------------</td>
<td>-----------</td>
</tr>
<tr>
<td>AGE</td>
<td>63</td>
<td>62</td>
<td>54</td>
</tr>
<tr>
<td>ETHNICITY</td>
<td>WHITE</td>
<td>ASIAN</td>
<td>WHITE</td>
</tr>
<tr>
<td>TIME OF ONSET OF HEARING IMPAIRMENT</td>
<td>9</td>
<td>DETERIORATION IN LAST 10 YEARS</td>
<td>AT BIRTH</td>
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APPENDIX 14

INFORMAL AND FORMAL SUPPORT FOR DUAL SENSORY IMPAIRED ADULTS AND OLDER PEOPLE
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<tr>
<td>JOHN PALMER</td>
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<td>NEIGHBOURS</td>
<td>THREE TIMES A WEEK</td>
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<tr>
<td>DAVID O'BRIEN</td>
<td>WIFE</td>
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<tr>
<td>MOLLY RICHARDSON</td>
<td>DAUGHTER</td>
<td>61</td>
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<tr>
<td>SARAH MILES</td>
<td>DAUGHTER</td>
<td>48</td>
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<td>EDNA GASH</td>
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<tr>
<td>CAROL MCPHERSON</td>
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<td>FRIENDS AND NEIGHBOURS</td>
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</tr>
<tr>
<td>MRS S</td>
<td>DAUGHTER</td>
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<td>GRANDSON'S WIFE</td>
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