3 Deaf-blind people

We just want people to know that we are normal human beings that need that little bit extra help. We can make our own decisions but we need help for day-to-day things.

(A deaf-blind woman, 1989)

The above quotation comes from a meeting we had with a group of deaf-blind people. We had originally arranged to interview two or three deaf-blind people individually because we had assumed that a group interview

Figure 4.7 Deaf-blind people: a holiday abroad
(Source: National Deaf-Blind League, 1988)
would be very difficult, if not impossible—clearly a measure of our prejudice rather than of their capabilities. The group was self-selecting and there was an even number of men and women. Each deaf-blind person had a sighted/hearing person with them to interpret.

◆ Reading
You should now read Article 22 ‘How I live with Deaf-Blindness’ by Patrick Murphy in Reader One. Patrick Murphy’s personal account of being deaf-blind raises many of the issues dealt with in this section.

3.1 Prevalence of deaf-blindness
There are no accurate figures relating to numbers of deaf-blind people. Klemz (1977) estimates that there are about 2,000 deaf-blind people in the UK, Lysons (1984) about 5,000. The Deaf-Blind Services Liaison Group (DBSLG), in their report Breaking Through (1988), estimate not less than 11,000 deaf-blind people in the UK. Yoken (1979) cites a Federal Government estimate of 21,000 deaf-blind children and adults in the USA. The DBSLG report states that anecdotal evidence would suggest that, in the London Boroughs, ten in every 200,000 people are recognized as deaf-blind, whereas the evidence from the small amount of research that has been undertaken places the estimate at five times that number.

On this basis the estimated deaf-blind population of the USA would be in excess of 56,000, whilst that of the UK would be approximately 13,000. There is no evidence to suggest that the incidence of deaf-blindness is significantly different in the two countries, so the comparison is reasonable. The US estimate of 21,000 is a Federal Government figure, whereas in the UK there is no official category of deaf-blind within the statistics gathered by the Department of Health. However, despite the difference in the means by which figures are arrived at, there does appear to be a serious underestimation of the actual number of deaf-blind people in both countries by the official agencies.

3.2 The deaf-blind community
‘Deaf-blind’ as a term does not adequately describe the different needs and experiences of the people to whom it is applied. The DBSLG report arrived at this working definition:

persons are regarded as deaf-blind if they have a severe degree of combined visual and auditory impairment resulting in problems of communication, information and mobility.

(DBSLG, 1988)

ITQ
Before proceeding, consider the following question:

What might be the important differences between someone who is born deaf and later loses his or her sight, and someone who is born blind and later loses his or her hearing?

Make a note of your answer before reading further.
Helen Keller commented that blindness cuts you off from things, whereas deafness cuts you off from people. To be deaf-blind by this analysis, then, would appear to be totally isolating. Without trying to minimize the effect of being deprived of both hearing and sight, the impact will vary depending upon life experience prior to the loss. For example, a deaf person who later in life loses his or her sight will be accustomed to a visual mode of communication, possibly sign language, and so would find the practical aspects of a transition to the deaf-blind manual (finger spelling on the hand of a deaf-blind person) relatively straightforward. An oral deaf person, reliant upon lip-reading, may experience more difficulty with this transition. A blind person who later loses his or her hearing, however, will probably have spoken language skills, and will be able to continue to use this form of expression. He or she will also be able to continue to use Braille without any difficulties.

The DBSLG report recognizes that deaf-blind people do not constitute a homogeneous group, and whilst a manageable definition of the term deaf-blind was necessary for the report, this definition in fact includes a range of people who will have experienced their deafness and blindness in very different ways, and, to a certain extent, their needs will be determined by the cause of their deafness and blindness and by the age of onset.

The National Deaf-Blind League (NDBL), in their 1988 report, divide the Deaf-Blind community into four main groups:

1. The person who loses sight and hearing in adult life (who will possess speech).
2. The blind person who subsequently loses hearing (who will also possess speech).
3. The deaf person who subsequently loses sight (who may be without speech).
4. The person deaf and blind from birth (who may also be without speech).

(National Deaf-Blind League, 1988)

The vast majority of people in Groups 1 and 2 are older people whose sight and hearing are failing with advancing years. Those in Group 3 are more likely to suffer from Usher syndrome, and those in Group 4 as a result of congenital rubella.

Rubella is a preventable disease and the vaccination is available free to girls over the age of 10 years and to women of child-bearing age. However, whilst statistics are gathered by the government, these only apply to a very narrow age group and it is not possible to use them to gauge satisfactorily the effectiveness of the school vaccination programme. This seems strange when one considers the virulence of rubella during pregnancy: in the rubella epidemic of 1963–1965, the incidence of rubella as a cause of deafness rose to 10 per cent of all those born deaf (Bordley and Hardy, 1969). Fifty per cent of those infants affected had heart disease, 50 per cent had hearing loss, 40 per cent had glaucoma or cataract, and 40 per cent had psychomotor retardation (Cooper et al., 1969).

Many of those children born with heart defects die in early infancy and their struggle is simply one of survival. The others are likely to be affected...
by more than one disability, with deafness more commonly present (68 per cent of children affected during the first trimester of pregnancy, 40 per cent during the second trimester, but deafness can result from rubella infection during any stage of pregnancy) (Bordley and Hardy, 1969). In the UK there is no need for doctors to inform the Registrar General of the numbers of cases of rubella they treat as, unlike many other countries, rubella is not a notifiable disease.

Usher syndrome has been estimated to affect three in 100,000 of the general population (Hallgren, 1959; Kloepfer et al., 1966), and to be the most common cause of deaf-blindness, affecting 3 to 4 per cent of all children born deaf (Vernon, 1969). It is a recessive genetic disorder characterized by a hearing loss present at birth combined with gradually deteriorating eyesight caused by retinal degeneration, retinitis pigmentosa (RP, or sometimes commonly known as tunnel vision).

There are two very important features of Usher syndrome: (i) it is only found amongst congenitally Deaf people; and (ii) RP is usually not diagnosed until early adulthood.

The effects of Usher syndrome are usually chronic rather than acute. The rate of retinal degeneration is difficult to predict, and children in whom the disease has not been diagnosed may be assumed to be clumsy if they bump into things, or intellectually slow if they fail to receive the information they need at school and fall behind their classmates. Early diagnosis is vital and, as all sufferers of Usher syndrome are congenitally deaf, then schools for the deaf would appear to be the ideal places to develop screening and support services.

Creagh Walker-Day (1982) surveyed residential schools for the deaf in the USA to find out if they had screening procedures for Usher syndrome and what support was available. Of the forty schools (68 per cent) that took part in the survey, 33 per cent screened annually, 19 per cent every 3 years, and 19 per cent on request. Eighty-four per cent of those diagnosed as having Usher syndrome were over 12 years old (51 per cent were 16 years and older), and only 51 per cent of those schools with a screening procedure had any form of post-diagnostic support.

A British survey conducted by SENSE (the National Deaf-Blind and Rubella Association) (Guest and Roper, 1988) was an attempt to discover the numbers of diagnosed pupils in full-time education. Their survey revealed that the majority of pupils were aged 11 to 18, with a predominance of those diagnosed at around 16 years of age. However, whilst the eldest was 23 years old, there were also two 5-year-olds, and the report concludes that this demonstrates that diagnosis does not have to wait until adolescence.

The SENSE report revealed high levels of concern amongst teachers about two factors:

1. Teachers had insufficient clinical information regarding the vision of their deaf pupils. The test for RP is quite specific and it is not easily picked up by a routine eye test. Furthermore, the technicians administering the eye test are usually not sufficiently experienced in testing deaf people; for example, they will attempt to communicate verbally in a darkened room.
2 Many teachers reported that they had been refused permission by the parents to tell the child of his or her diagnosis. The report concludes that parents either could not communicate with their children or had not come to terms themselves with their child's diagnosis. The question must be raised as to what kind of support is available to parents in this situation.

With continuing education policy of integration, and the attendant closure of more residential schools for deaf children, surveys such as this will be much more difficult to conduct in the future and thus early diagnosis of Usher syndrome even more problematic to make.

3.3 Deaf-blind people and the Deaf community

We discussed the question of deaf-blindness with all the groups we interviewed for this unit, and the picture that emerged is that deaf-blind people are viewed with some sympathy by the Deaf community but are, nevertheless, isolated from it.

We began the discussion with this statement: 'Some people say that to be deaf-blind is a terrible personal tragedy, and there is nothing that anyone can do to help'. We invited the different groups to consider the statement, and to give us their own views. Everyone thought that it was a terrible personal tragedy, but their response as to whether deaf-blind people can be helped was divided into two recognizable categories:

They are quite happy by themselves Sometimes they will sit in a circle together talking on each other’s hands, but usually I think they prefer to sit alone.

(A sighted Deaf man, 1989)

The view expressed in the above quotation is one that a number of people considered to be accurate. These were mostly Deaf people who could not claim any personal acquaintance with deaf-blind people, but had seen them, perhaps in the Deaf club. They were also mostly men, and we will return to this point of gender-specific behaviour below.

The second major response was that deaf-blind people received quite a lot of help really, for which they were grateful, and with which they were reasonably content:

We help them here, members and others, they help, yes they do help. We have deaf-blind holidays and they are quite happy with them. Hearing people help, and volunteers; it is very good. For born deaf-blind it is easier and they are quite happy with their lot in life, but if you suddenly go blind it can be a shock at a late age. But they know if they are born deaf-blind then they will be like it for life, so it’s easier for them.

(A sighted Deaf woman, 1989)

We have a lot of deaf-blind here, mostly on Sunday for church. They enjoy their lives I think

(A sighted Deaf woman, 1989)
People who supported this view had either first-hand experience of deaf-blind people, or attended a club where there was a facility for deaf-blind people organized by social workers. The examples given to us of situations in which Deaf people had directly offered assistance to a deaf-blind person were very few and mostly some time ago. The respondents in this category were almost exclusively female, which leads us to speculate that gender-specific behaviour is a major contributory factor.

Acquaintance with deaf-blind people by Deaf men was much more likely to be from a distance, whereas acquaintance by Deaf women was almost always practical and of a personal contact nature. This is consistent with traditional socially constructed gender roles, with women being conditioned to be carers and practical helpers, whilst men are allocated supervisory or leadership roles.

Only one person offered an alternative view. A young Black Deaf man told us:

It's the wrong attitude, it's really the wrong attitude. Whenever we do have a deaf-blind person in the Deaf centre, people really don't bother to help, they leave that person alone and I think that is a serious problem. It reminds me of an incident where I introduced a girl who was losing her hearing as well as her eyesight. I brought her into the Deaf centre and tried to get her to talk, but Deaf people didn't bother with her. Then there's Harry who's deaf-blind, he comes in, and Gill who's suffering from Usher syndrome. I try to talk to them, and take them around the club to talk to other people, because otherwise they are just left to sit by themselves with nobody to talk to. It's just not right.

(A young Black Deaf man, 1989)

Figure 4.8 Deaf club members in conversation with a deaf-blind person
(Source: courtesy of the British Deaf Association)
We put the statement that ‘.. to be deaf-blind is a personal tragedy and there is nothing that anyone can do to help’ to the group of deaf-blind people. Their response was very clear:

The statement you read out to us is the very attitude we are trying to fight against. It is the reason deaf-blind people are left out of things at Deaf clubs, because people think there is nothing they can do other than leave them sitting.

(A deaf-blind woman, 1989)

Their experience of attending Deaf clubs was very negative:

I can only say that in my time I was the only person who was deaf-blind to go to the Deaf club in my home town. I do not think it is right for deaf-blind people to go to Deaf clubs because they will be left out and left quiet. It is better for them to go to a deaf-blind club.

(A deaf-blind man, 1989)

That was my experience also, I went to Deaf clubs and was never included in the activities. I think what they do is too sight oriented, you cannot really join in their activities.

(A deaf-blind woman, 1989)

The guide would take me to the Deaf club, then leave me alone whilst they went off to talk to others. I was left there until it was time to go to the pub.

(A deaf-blind man, 1989)

I used to go to the day centre where I lived and there was a Deaf club down there every Friday night. I was put in touch with them but they did not think it would be any good because of my sight problems. They said I needed to be with deaf-blind people, but in my town I didn’t know anybody else. I wanted to meet with other deaf people and use sign language but the Deaf there didn’t want to bother. The staff at the day centre were keen to help but they had lots of other people to deal with.

(A deaf-blind man, 1989)

When I went to the Deaf club in my area I found that I was not accepted. I would be introduced to deaf people who would say that they had to go and do something right now but they would come and talk to me later—they never did.

(A deaf-blind man, 1989)

The central theme running through the information given us by deaf-blind people was very clear: they had made a number of attempts to include themselves in the activities of Deaf clubs and had been met with rejection and isolation. This was regardless of whether the deaf-blind person was born deaf-blind, born deaf and later became blind, born blind and later became deaf, or born hearing and sighted later to become deaf-blind. The significant factor was that the treatment they received did not appear to be affected by their previous body image/sensory identity. If this is the case throughout the Deaf community, and we have no reason to believe it is not, then the future for those Deaf people with Usher syndrome would appear to be rather bleak, characterized by diminishing social contacts and isolation while they are still amongst people with whom they may have been friendly for many years.
The nature of the ‘Otherness’ of deaf-blind people in the Deaf community would appear to be that they are the ‘Other’ to be avoided, to be ignored. But is it more complex than that? Goffman (1968) describes the way in which ‘stigmatized’ people develop strategies in their encounters with ‘normals’, and in which the ‘stigmatized’ are expected to take responsibility for managing the encounter. Higgins (1980) states that encounters between deaf people and hearing people are characterized by deaf people having to adapt to the assumptions of hearing people in order to maintain the interaction as ‘nothing unusual is happening’, or manage the interaction because ‘something unusual is happening’.

The relationship between Deaf people and deaf-blind people is that of the ‘something unusual is happening’ variety, and the claim by deaf-blind people that they are ignored and avoided by Deaf people is something that Deaf people experience in relation to hearing people. Goffman, however, asserts that the ‘stigmatized’ are labelled as deviant by ‘normals’, and are the subject of anger, criticism and blame. This is certainly not a feature of the relationship between Deaf people and deaf-blind people we have interviewed.

There may be a number of reasons for this—we identify two. First, society generally is reasonably well disposed towards blind people in a sympathetic, patronizing way. This is not unlike the attitude we found amongst Deaf people and it may be that their attitude simply reflects the general view of society towards blind people. Second, and perhaps more likely, is that there is an increased awareness amongst Deaf people about the impact of blindness on someone with a hearing loss. Deaf people operate in a visual medium and any interruption of that is serious because it threatens every aspect of their lives. It could be that being with deaf-blind people raises for them too many fears and anxieties about their own future. When one considers the relatively late onset of blindness caused by Usher syndrome, and the general deterioration of eyesight in old age, the prospect of being without hearing and sight at some point in their lives must be much more keenly felt amongst Deaf people than amongst hearing people.

One Deaf person told us:

I know someone, a woman I used to go to school with. I hadn’t seen her for a while and when I met her again I was shocked to see she was blind. It really frightened me, what can we do when we become blind?

(A Deaf woman, 1989)

3.4 Services

Yoken (1979) refers to deaf-blind people in the USA as the ‘invisible minority’. This is even more true in the UK, where, not only are statistics not gathered by the government, there is also no legal definition of deaf-blindness and no Acts of Parliament that deal specifically with the needs of deaf-blind people. Service providers usually rely upon Government Acts and statistical information to provide the incentive to develop their service profiles. The 1970 Chronically Sick and Disabled Persons Act did have a section which directed local authorities to inform themselves of numbers of deaf-blind children in their areas and make educational provision for them,
if possible, in state schools. However, this part of the Act was never implemented and it was repealed in 1981. Deaf-blind people are expected to fit into the services provided for deaf people or blind people, a fact that dismays many deaf-blind people and those who work with them. One person in the interview group said:

I went to a Deaf school for a year when I first came out of hospital and they were quite unable to teach me. They had no idea what approach to take. I couldn’t speak, I couldn’t lip-read, I couldn’t read the blackboard, I couldn’t read their text books, they were quite lost. Then I went to blind school and they were able to spare the time to give me individual tuition but I was still unable to join in with the rest of the class.

(A deaf-blind woman, 1989)

The DBSLG report made comprehensive recommendations, which would locate the responsibility for services with local authorities in collaboration with voluntary agencies. The recommendations range from identifying numbers of deaf-blind people, through multidisciplinary assessments and self-advocacy schemes, to the implementation of training and support packages for staff in residential homes and hospitals. It remains to be seen whether any of these recommendations will be realized in action by central or local government.

The deaf-blind people we interviewed were in agreement with the need for an over-arching strategy for services, as recommended in the DBSLG report, and they produced their own list of the ten most important needs of deaf-blind people, as compiled by the deaf-blind consultant to the National Deaf-Blind League, Patrick Murphy. These needs are:

1. Education
2. Rehabilitation
3. Interpreters
4. Guides
5. Social intercourse
6. Public awareness
7. Responsibility
8. News and information
9. Daily living skills
10. Hobbies

They had concerns at different levels about services. About education they raised the issue of a need for more specialist teachers because education for deaf-blind children is most effectively achieved with one-to-one teaching. A further concern was where to educate deaf-blind children.

Whether to integrate or educate them separately is an important issue. Deaf-blind children need to begin education very early, but do you send the child away from its parents at the age of three to go to a residential school, or leave them at home with their parents and lose the early training?

(A deaf-blind woman, 1989)

The area of services about which they felt most strongly was that concerning social workers, guides and interpreters. The confusion of the roles of social workers and interpreters is ever present in the Deaf
community generally, and to a certain extent this is also true for deaf-blind people. (This issue will be discussed in more detail in Unit 7.) But, although they identified social workers/guides/interpreters as being extremely important, they clearly wished to be in control of their own lives and were therefore very anxious about the quality of any relationship they might have with these people:

I think what we need is a true, trustworthy friend, at least one. Somebody that understands and doesn’t get impatient.

(A deaf-blind man, 1989)

Not someone who is paid because it might not be the right person. It should always be a true friend.

(A deaf-blind man, 1989)

A paid guide is not as true a friend as someone who is not paid. Social workers are paid and I have found some social workers that I do not like. They do not know how to help deaf-blind people.

(A deaf-blind man, 1989)

Very often social workers get the idea that because they have been trained they are perfect, and that, of course, is not true. They still have to learn how a deaf-blind person wants them to do things. We all have our likes and dislikes, so I would prefer a friend to a social worker.

(A deaf-blind woman, 1989)

But the subject also raised a number of fears that perhaps altruism alone may not be sufficient to provide for their needs, and that some formalized arrangement might also be necessary.

Although, a paid person could be more reliable perhaps because if they do not do what they are supposed to do they would not get paid.

(A deaf-blind woman, 1989)
There are times when to have paid help can be a great advantage. I am thinking more about interpreters than a guide, you want to go to a conference or a meeting where you need an interpreter and it is good to be able to ask someone to do it and offer to pay them. I feel it is asking a lot to expect them to finger spell for a whole day, for love.

(A deaf-blind woman, 1989)

This area of personal help highlights the vulnerability of deaf-blind people because, regardless of how intelligent, clear-thinking and physically active they may be, they are dependent upon the assistance of another person in order to do many of the things that hearing/sighted people take for granted. Their concern is for high levels of trust rather than for professional skills or expertise. By their attempts to be involved in Deaf clubs, deaf-blind people are clearly reaching out to the Deaf community with the hope of establishing trusting relationships. The position of deaf-blind people as the ‘Other’ to be avoided and ignored in Deaf clubs would seemingly militate against these relationships developing:

At the Deaf club Deaf people are involved in many different activities. It is true that deaf-blind people cannot join in all of them, but a Deaf person could tell us what was happening. Then we would have some choice and could make more of a contribution.

(A deaf-blind woman, 1989)

**ITQ**

Now return to the questions we asked you in the first ITQ on page 7–8.

Would you answer the questions in the same way now in respect of deaf-blind people? If not, try to identify what it is that has caused you to alter your view. If your answers are broadly similar to those you came up with at the beginning, try and think of some new information which you have now, but did not have at the beginning, or some facet of the debate which you had not taken into account. Make some notes and keep them for Activity 4 at the end of this unit.