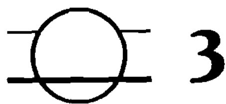
DISABILITY DISCOURSE; CORKER, FRENCH ED; OPEN UNIV. PRESS, 1999

 3

# The wind gets in my way

**Sally French**

## introduction

Being visually disabled gives rise to many difficulties when attempting to communicate with sighted people. These range from obvious problems, like being unable to recognize people, to more subtle matters like failing to share similar experiences and being unable adequately to describe one's own reality. Conflicting discourses arise when sighted people define what is 'acceptable' and 'normal' behaviour for a visually disabled person and use these definitions to contest that person's identity.

As a small child I had a dislike of going out on windy days. My mother, no doubt exasperated, asked me why this was so, to which I replled 'The wind gets in my way.' I do not remember this incident but it is recalled, as an amusing family story, to show what a quaint and peculiar child I was. As a visually disabled adult I know exactly what I meant. Going out on windy days is more difficult. The wind makes a noise which obscures the small auditory cues which, though rarely appreciated until they are absent, are so helpful when walking about. Wearing a hat which covers the ears (as no doubt I did as a child) exacerbates the problem. I was right, the wind does indeed get in my way.

Interpreting the visual world without much sight is difficult, especially for young children who, inevitably, lack experience. Nobody interpreted my fear of walking over zebra crossings correctly, nor my dread of stepping near the edge of flower beds – and yet to me zebra crossings were steps to fall d o and flowerbeds dark, bottomless pits. A common feature of life as a visually disabled person, which starts very early, is having constantly to explain oneself and yet rarely having one's experiences confirmed. There were other behaviours which I knew were sensible but which I had no words to explain. 'Not looking where I was going' was one. It seemed particularly perverse to the adults in my life that, as a visually disabled child, I constantly looked at the

ground! What is more, I always trailed behind out of everybody's sight. As a visually disabled adult, however, I have no difficulty explaining these 'aberrant' behaviours. The ground is where most of the danger lies; by looking down I have the greatest likelihood of seeing objects or steps in my path. True I sometimes get slapped in the face by an overgrown hedge, but ground objects are far more common and my distance vision is so restricted that looking down is much more functional than looking up. As for lagging behind, well, following other people, looking at what they do, observing their feet to see where they tread, is a sensible way to behave. It is they, not I, who are finding the steps, it is they who are finding the way.

How often these conflicting exchanges occurred I cannot say, but I can still experience the feelings they induced; feelings of isolation, difference and shame. The feelings were made worse by my inability to explain my behaviour, even to myself, although I always knew that I was right and 'they' were wrong. Experiences such as these had an adverse effect on my self-esteem and confidence which only began to abate when, in an abusive boarding school at the age of nine, I met other girls like me. Living our lives together, having them as my friends and knowing they shared my world was nothing short of joy. These deeply rooted friendships are still important; they have buffered my life.

## Communication in a sighted world

It is estimated that most communication between people occurs at the non-verbal level, and that if verbal and non-verbal behaviours conflict people tend to believe the non-verbal messages as they are far more difficult to conceal or control. Visually disabled people, to varying degrees, do not have access to non-verbal communication and must rely much more heavily on what is actually said. Exceptions to this are the non-verbal qualities of voice (pitch, tone, speed, volume and so on), where much information about the person's emotional state can be gauged, and touch – which social norms largely prohibit outside intimate social and sexual contexts. As visually disabled people we tend to lose the emotional content of messages, though the non-verbal qualities of voice, and even the sound of someone walking, or shuffling in a chair, can give a great deal of information.

It is difficult for us, particularly in group situations, to assess people's attitudes and moods because of the lack of non-verbal information. If I make a comment in a meeting, for example, I am frequently unaware how the comment has been received especially if nobody answers me directly; whether they are smiling and nodding, or looking angry or bored are beyond my perceptions. Neither can I see if people look tired or unwell. Non-verbal communication is largely learnt, so our own non-verbal behaviour may be reduced or different from that of sighted people – I have variously been told that my non-verbal communication is 'impoverished' and 'no different' from that of others. Lack of non-verbal behaviour can disturb interaction, particularly in

group situations and where visual disability is not understood or accepted. It is, for example, very difficult to contribute to group discussion without interrupting people as 'turn taking' is governed by subtle visual cues – something I only learnt through studying psychology. This can cause hostility in others and embarrassment in ourselves and can lead us to remain silent.

Noisy, crowded environments are particularly difficult. The background noise obscures the voice, which cannot be compensated with non-verbal communication. It also obliterates the auditory cues that we use to orientate ourselves and to move around. Communication in noisy environments often demands the use of both verbal and non-verbal communication. Visually disabled people cannot, for example, hear speech when sitting opposite someone in a train because of the inability to supplement the voice with non-verbal information such as that gained from lip reading. When I am lecturing to large groups of students I cannot hear their questions, not because I am deaf, but because I cannot supplement what I hear with what I see. Neither can I make eye contact with the person who is speaking.

An example from my own experience, which illustrates the importance of non-verbal communication, occurred when I gave a 'one-off' guest lecture to a group of students who were undertaking a health service management course. When the course leader sent me the students' evaluation of my performance I was shocked to discover how bad it was – in my 15 years of teaching I had never received such a negative judgement. The students had found me 'distant', 'cold', 'aloof' and 'uninterested'. Admittedly I was tired, but I was well prepared and delivered what I thought was an interesting session. I certainly did not feel any of the emotions with which I was credited. So what could be wrong?

There was only one obvious difference between this lecture and the many hundreds I had given before: I had not explained my visual disability. Usually I tell students that I cannot see them as individuals and that none of their non-verbal language will reach me. I encourage them to speak up and never to be afraid of interrupting me. But this time I had failed to do so. As someone who has been visually disabled from birth, it is difficult for me to judge the impact which distorted non-verbal communication might have on a sighted audience, but most people to whom I have related this story are convinced that the problem lay entirely with my lack of explanation of visual disability. The likelihood of visual disability rarely features in people's interpretations of our behaviour; instead we are credited with negative personal characteristics.

White sticks can be used to supplement communication. I use a white stick intermittently as a symbol of visual disability. I use it to influence people's behaviour, for example to attract their help or alert them to take care. Often the symbolism of the white stick supplements verbal information. When I want help to find a building, for example, saying 'I can't see very well', with a white stick displayed, gives a more powerful message than saying the same words without a white stick. The white stick is not, however, powerful enough to prevent people giving visual directions both verbally and

non-verbally – much to their own embarrassment. Although some people are better than others, I find it best to ask directions of other visually disabled people who will provide me with appropriate non-visual and near-visual cues. Saying 'turn left when you get to the rusty gate' is likely, for example, to be far more helpful than saying 'turn left when you get to the police station'. Contrary to biblical predictions the blind can lead the blind and it is very unlikely that either will fall in the ditch!

I have used a white stick for 30 years and have noticed a change in people's responses especially in recent times. It used to be the case that people assumed total blindness, but now the question 'are you partial?' is common. Similarly, if I am treated as a totally blind person and I say 'I can see a bit' this does not give rise to surprise. Despite this, I do not feel that people will understand or believe if, having used a white stick to cross a busy road, I fold it up and read a book. The feeling of discomfort to which this gives rise in the presence of others is very strong, although I have rarely been challenged.

Such a challenge did, however, occur a few months ago. I was meeting a friend for lunch on a very busy street. The pavement was crowded so I used my white stick to avoid bumping into people as I walked along. Being rather early for my appointment I folded the stick and went into a shop to browse around the books. I was approached by a middle-aged woman who, having seen me in both situations, challenged my behaviour with some hostility. I gave a terse, rather angry, explanation to which she replied, with a very mild voice, that she had not understood but that now she did.

Occasionally people (usually old people) ask questions such as 'How long have you been like this?' or want explanations of cause. Others find it hard to believe that only a small amount of help is required. The question 'Which road am I in?', for example, is frequently followed by the question 'Where do you want to go?' Others seem to equate visual disability with illness and dependency. I was recently told by someone who was helping me to find the entrance to a railway station that it was a good job he worked for the Red Cross and another was incensed that 'people like me' were compelled to work. On a recent occasion, when using a white stick in the council buildings, I was told 'You're going the wrong way, you need the Social Services Department'!

Responses such as these are, however, relatively rare, especially in recent times. Most people I approach are willing to help in any way they can and many volunteer. Mostly I am treated with respect. Taking control by stating, with assurance, exactly what help is needed seems to discourage condescension and patronage and induce relaxation and confidence in those whose help is sought.

My feelings about using a white stick are mixed. I regard it as a symbol of independence rather than a symbol of dependency. It is understood throughout the world and has assisted me in travelling with confidence to unfamiliar countries on my own. I constantly feel, however, that others are judging me and thinking I am a fraud, though this is rarely voiced and may not be the case. I am reluctant to use the white stick in the vicinity of sighted

people I know, for fear of what I think might be their judgement. I feel, but do not believe, that, as someone who can see (albeit minimally) I should not be using it.

These perceptions of what other people think were reinforced in a recent *Songs of Praise* television programme which came from Exeter Cathedral. One of the people interviewed was an instructor from the training centre of the Guide Dogs for the Blind Association in the city. He explained how he, as a sighted person, worked the dogs, as a blind person would, to ensure their competence and safety. He went on to say that he always identified himself as a trainer, if people tried to help him, as he thought it would be detrimental to visually disabled people if the public thought he was visually disabled and subsequently saw him looking in a shop window. The message, that visually disabled people who use aids, and yet can see, are frauds, was broadcast to the nation even though the Guide Dogs for the Blind Association. actively encourage people with my degree of vision to apply for training.

## Contesting and confirming our identities

Our attempts at communicating within a sighted world give rise to isolation and lack of acceptance by sighted people. I do not think I would ever be described as an isolated person, neither would I describe myself in that way – I have many good friends. I have relatives, I have work colleagues, I go on holiday to exciting places with other people – and yet visual disability is, for me, in some situations at least, an isolating experience. This is largely due to my inability to recognize people and to see and respond to non-verbal language. It is also due to other people's lack of understanding and acceptance of visual disability and their lack of adaptation to it.

I have lived in the same house for 16 years and yet I cannot recognize my neighbours. I know nothing about them at all; which children belong to whom, who has come and gone, who is old or young, ill or well, black or white. When I had a painter in recently he told me more about the 'goings on' in my road than I could ever know. I am a lecturer and yet I cannot recognize my students. I explain the situation and we work together well but I cannot greet them, smile at them, give them a friendly wave, and I cannot receive their gestures in return. I work within a bustling, vibrant environment and yet I often feel detached. I am surrounded by people, some of whom say 'Hello', but I rarely know who they are.

On occasions I have made efforts to find solutions to problems such as these. On moving to my present house I informed several neighbours that, because of my inability to recognize them, I would doubtless pass them by in the street without greeting them. One neighbour, who had previously seen me striding confidently down the road, refused to believe me, but the others said they understood and would talk to me if our paths crossed. For the first couple of weeks it worked and I was surprised how often we met, but after that their greetings rapidly decreased and then ceased altogether. Why this

happened I am not sure, but I suspect that my lack of recognition strained the interaction and limited the social reward they received from the encounter. For my part, my inability to see them approaching meant that I was invariably jolted abruptly from my thoughts when they did speak which, as well as feeling unpleasant. affected the normality of my response.

My neighbours were presented with a learning opportunity to which they initially responded but then declined. If they had persisted it is likely that the difficulties would have diminished; I would have recognized their voices and getting to know each other better would have reduced the tension we all experienced. Simply informing people about visual disability is seldom enough to change significantly their behaviour.

In 1996, when on holiday in Greenland with a friend, Daisy, who is totally blind, I did, however, have a very different experience. We were to join a group of 15 people and would take part in various outdoor activities. Precise information was difficult to get, the tour operator said that he had never had any visually disabled tourists going to Greenland before but that the Greenlanders were 'very friendly'. He was optimistic, but when questioned closely about possible difficulties, would not commit himself. The holiday was expensive but, drawing on each other's strength, we booked it up.

On the first day we went on a long, but easy, walk. Daisy held a white stick most of the time. I guided Daisy but displayed a white stick on several occasions to attract help lor myself, for example when boarding a boat. The other people on the tour willingly gave their help, though their interaction with us was tentative and shy. By the second day I realized that they must have been observing us closely to understand our situation. From that day on their help was spontaneous and absolutely right. When things became difficult we both had a guide, but as soon as we could manage their help was appropriately withdrawn. The pace of the holiday was slow and we were given opportunities to experience things in our own way. The boat was steered near an iceberg so that Daisy could feel its length, I was always ensured the best position to see, and the other tourists, even with minimal English, described to us what they saw. We felt totally relaxed and did not use a white stick for the remainder of the holiday. This experience has led to a marked shift in my judgement of the capacity of sighted people to comprehend the complexities of visual disability. When we returned home I rang the tour operator to tell of our success. He was, of course, delighted, and said that people who visited Greenland were 'not your average tourist'. Their response was certainly very different from that of my neighborrrs.

Being with sighted people can be a very relaxing experience in some respects; they can find the way, lead us around, drive us in cars, but our different experiences of the world can threaten the enjoyment of our interactions. A few years ago I went on holiday to the Channel Islands with a visually disabled friend. She had always been on holiday with sighted people before but, although we were restricted and had many hassles resulting from visual disability, she claimed that the holiday had been more enjoyable and successful than any other she had had.

We cannot always engage in the same activities as sighted people, we cannot do things as fast, we need more time to see, and we need opportunities to use our other senses to the full. When we are together, getting lost and having problems, we are ***engaging*** with the world far more than we ever could from a car or at someone else's pace. We might not do as much, but what we do is on our terms and at *our* pace and without any need to explain ourselves. It is difficult, when with sighted people, to meet our own needs without curtailing theirs and it is easy for relationships to become unequal leading to feelings of isolation, injustice and boredom. The behaviour of the people on the Greenland trip was sophisticated; they gave us the help we needed, they helped us to experience things on our own terms, while at the same time respecting our capabilities, autonomy and independence.

## Conclusion

Visual disability has a profound effect on communication, not only in terms of everyday interaction, but in terms of what we know, what we experience, how we behave and who we are. The aids that we use – white sticks, monoculars, guide dogs – also have a profound effect on how we feel, how we behave and how others respond to us. When groups of visually disabled people come together the 'rules' of social discourse are changed. People may, for example, shout out somebody's name in order to find that person, or walk around uninhibited where the act of bumping into someone and asking 'Who are you?' solves the problem of recognition. We have our own humour, and a unique history of 'special' schools, 'special' colleges, 'special' equipment, 'special' jobs and 'special' ways of doing things. Perhaps this indicates the existence of a 'blind culture' where, in a similar way to 'Deaf culture', social rules and behaviour take on a specific form to overcome social barriers and where, despite our great diversity, common experiences in our past and present lives bind us together in so many ways.