

Disability and Communication: Listening is not enough

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This is the penultimate version of a chapter that was first published as: Swain J. and French S. (2004) Disability and Communication: listening is not enough. In Barrett S., Komarony C., Robb M. and Rogers A. (eds.) Communication, Relationships and Care: a reader.

The usual starting point for professionals in considering 'disability and communication' is the development of effective communication. The improvement of health and social care services is equated with better conveyance of information and, quintessentially, better listening – improved skills and their use. The imperative of effective communication has had clear mandates for many years and it would be difficult to find a text within the professional literature that did not emphasise the need to listen to clients (or patients or service users).

Taking a more critical stance is not an easy position as it seems to fly in the face of common sense. There are, however, a number of related foundations for taking such a stance which we would like to explore in this chapter.

- The dominant, common sense notions of what it means to be disabled have been challenged by disabled people themselves.

Disabled people and their allies have developed a social as opposed to an individual, or medical, model of disability.

- The barriers to effective two-way communication are ingrained in institutional discrimination, for example in the ways in which meetings are conducted. 'Listening' could, in a broader sense, involve a collaborative approach to remove such barriers between professionals and clients.
- The barriers to effective two-way communication are also ingrained in the power relations between professionals and clients. For example professionals have control of the timing of consultations and how much of the budget is spent in making communication accessible.
- Active listening is responsive - it can transform health and social care into a working alliance between disabled clients and professionals and create a communication environment in which disabled clients have control.

Understanding Disability

Disabled people and their allies have generated a social model of disability over approximately the past 30 years. We shall characterise this model here by comparing it with the individual, and particularly the medical, model of disability, that has been

increasingly challenged but still remains the dominant view of disability. So, looking from the two viewpoints what is 'the problem'? From the point of view of the medical model it is the individual, the impairment or the medical condition. Problems of communication emanate from the fact that the individual is deaf, or 'has aphasia' or is a 'stroke victim'. From the viewpoint of the social model, the problem is the disabling society that is geared by and for non-disabled people – for 'normal' communication. What of individual change? The medical model is orientated towards normality – to walk, to hear, to see. The social model, however, is directed towards transforming consciousness, that is towards the affirmation that disability is a political issue. What of changing services? From the medical model, what is needed is more of the same, for example more speech therapy provided by trained speech therapists. From a social model viewpoint, it is control by disabled clients of their own services that is of paramount importance, for example direct payments has been a significant development for many disabled people. And political change? From the medical viewpoint it is empowerment of powerless people by those who possess the power – power handed down. Looking from the social model, the politics of change are in the struggles by those who lack power. And finally what of the future?

From the viewpoint of the medical model it is the maintenance of a normal society with more effective services to cure or care for those rendered or deemed to be abnormal. For the social model the vision of the future is full participatory citizenship and equal rights for all disabled people.

There has been considerable discussion about the social model over the years (Swain et al 2003). Mairian Corker's work is of particular relevance to the discussions. She has argued that social model accounts have tended to exclude those people for whom language and communication are the foundations of oppression and exclusion (Corker, 1998). Corker argues that this exclusion is perpetuated by the disabled people's movement which has failed to analyse culture and discourse in the construction of disability.

She writes:

Without the full integration of cultural processes into the model, reference to the cultural construction of disability and deafness seem somewhat hollow . . . (1998: 38)

It is important to recognise, however, that Corker and others, who have an interest in language and discourse, are not attempting to abandon the social model but rather are 'encouraging its reflexive use.' (Corker, 1999: 209) This involves the recognition and

liberation of silent 'voices' and a greater range of positions from which disabled people can subvert forces of oppression and discrimination.

In terms of the analysis in this chapter, the unfair and unequal treatment of disabled people is not just built into institutional organisations, and their policies and practices, at a structural level, it is built into the language, communication and client-professional discourse. Simply to improve professionals' communication skills, for instance listening skills, may only strengthen unequal client professional relations. There are many ways that this can be manifest, as we shall see below, but it is underpinned by control by the professional. Very polished language (on the part of professionals), for instance, can be controlling – they may seem far too 'nice' to contradict when they have such excellent communication skills. Norell (1987) believes that the desire to say the 'right' thing and respond in the 'correct' manner has become something of a preoccupation. He believes that a spontaneous response can be superior to the 'painfully laboured, contrived, self-conscious effort of the 'trained' doctor' (1987:14) and that one measure of a good relationship is that it can survive disagreement and conflict. He states:

The doctor who decides for instance not to conceal his disappointment or disapproval may be helping to develop a more productive relationship than if he were to assume the outward appearance of tolerance while fuming inwardly.

(1987:14)

Harry (interviewed by French, forthcoming) speaks of an incident where a physiotherapist spoke to him in an unorthodox manner which, nonetheless, led to a good result:

I was in the physiotherapy department, they all knew me well, I was part of the furniture, and I remember saying to one of the physios, 'Why isn't there any counselling?' I said, 'There really should be counselling offered to people who've had strokes and who have communication problems.'.....and this physio said, 'Harry, I'm fed up with you moaning about this, I agree with you entirely but why don't you do something about it? Why, don't you do a counselling course because I think you'd be really good at it?.....so stop moaning and do something about it.' I wandered around for weeks afterwards thinking, 'I wonder' and 'maybe'. The thing that helped me so much was her belief that I could do it.

Harry subsequently became a fully qualified counsellor and now works with people with aphasia.

Norell, talking of the communication of professionals believes that:

Attention is focused on performing, on ways of doing things, on the process of caring, to the virtual exclusion of observing long-term results. (1987:6)

Experiencing Disabling Communication Barriers

This takes us into disabled people's experiences of services, concentrating on barriers to communication, recognising that any analysis of barriers to communication needs to identify the complexities of the communication process itself and the diversity of disability. Such an analysis also needs to recognise the inequality of professional-disabled clients relationships.

Professional dominance can be seen in assessment procedures where, for example, the professional's observations are viewed as objective whereas the patient's perceptions are viewed as subjective and where pseudo-scientific language serves to mystify and confuse service users (French, 1993). Because of the specialization of the various professional groups, definitions of need tend to be narrow, their scope being dictated by specialized knowledge and interests (Ellis, 1993). The needs of disabled

people, on the other hand, tend to be multifaceted. As Marsh and Fisher point out:

If the process of assessment becomes one of professional discovery of 'need', rather than a negotiation of problems, then users tend to feel hemmed in by the definitions used to describe their circumstances and trapped by the choices they are faced with. (1992: 50)

Attitudinal barriers are commonly referred to by disabled clients. Boazman had mixed responses from health professionals when she became aphasic following a brain hemorrhage:

Their responses towards me varied greatly, some showed great compassion, while others showed complete indifference. I had no way of communicating the fact that I was a bright, intelligent, whole human being. That is what hurt the most. (1999: 18-19)

Similar mixed experiences were reported by people with aphasia interviewed by Parr and Byng. One person, talking of doctors, said:

. . . when you can't communicate they treat you like a kid and that is just so frustrating - A handful of doctors were just awful.

You just wanted to say, 'Do you know what this is like?'

(1997: 74)

Pound and Hewitt (forthcoming) write of the equation of communication disability with 'having nothing to say' and being stupid which they believe is a 'well trodden embellishment of the 'Does he take sugar' syndrome.'

In another small-scale study involving people with speech disabilities, it was found that most difficulties were encountered within medical services and doctors' and dentists' receptionists were singled out for particular criticism. Mary, one participant, recalled:

My most embarrassing incidents have been with my doctor's and dentist's receptionists. I have had more trouble with them than with any other group. They were impatient and rude when I tried to make appointments, and would talk to my carer when I was trying to ask questions. (Knight et al, 2002: 19)

One participant described his encounters with hospital consultants:

They have excluded my carer from any discussion despite me indicating that I preferred to have my carer lip-read to avoid having to use my oesophageal voice. (2002: 19)

Another common complaint of the research participants in this study was the means of access to services that generally depended on the telephone.

People with speech impairments are often compelled to wait long periods of time for the communication equipment they need. A survey conducted by *Scope* (Ford 2000) found that nearly a fifth of people waited for more than a year. Professionals may also have control of when the equipment can be used. One of the research participants said:

Physiotherapists at school have recommended the Delta Talker be removed from situ during travelling because of possible safety problems. They also used to request removal of the talker at meal times. (Ford 2000:29)

Deaf people have complained about the insistence of professionals that they use speech rather than sign language. A deaf person interviewed by Corker states:

I hated learning speech – hated it – I felt so stupid having to repeat the s,s,s.....I was asking myself ‘Why do I have to keep going over and over it, I don’t understand what it all means’.....It was just so stupid, a waste of time when I could have been learning more important things. (Corker 1996:92)

In interviews conducted by Sally French (French, forthcoming), Sandy and Sue spoke of their experiences of occupational therapy:

I've often thought about OTs in rehab, if only they could think about the context from which their patients came. I was received as head of department of a girls' comprehensive school, head of physical education, and this OT said to me, 'Now you've really got to learn to type because that's what you'll be doing.' She negated the whole context of my professional life - I was just a patient. Just because someone has had an accident or an illness doesn't mean that they've changed one iota. I went in as a gymnast and a sports person, that hadn't changed, it was just that I couldn't do it anymore. There was no acknowledgement of what my life was about or how to shape my new future. They had a routine. It was almost like, 'She's got fingers, she can type.' I couldn't identify with it, there was no link with anything to do with me. (Sandy)

It was a case of being treated like a patient. I felt like my feelings were being ignored, that they were just going through a routine and they would give me exercises to do

which I couldn't understand the purpose of because they didn't explain. I had enough speech to ask, but I didn't ask, because I didn't have the confidence to ask. (Sue)

Information can also be given in an insensitive way as Joan (interviewed by French et al) explained:

When I came back for the negatives, oh it was terrible. He lifted them up to the light and he said to the nurse 'Macula degeneration in both eyes, sign a BDS form' or whatever it is. Then he turned to me and he said 'There's nothing we can do about it.' He said 'You'll always be able to see sideways but you've got no central vision'.....So I came home feeling very upset about it. (1997:37)

Being unable to access information is a problem faced in all areas of life by visually impaired people, with potentially hazardous consequences of unreadable notices and loss of privacy when documents are unreadable by the intended recipient. Vale (2001) reports that appointment letters continue to be sent out in standard-size print even by many hospital eye clinics, and only one third of NHS hospitals offer general patient information in large print.

It is important to recognise that social divisions, for example gender, age and ethnicity, intersect disability, and also produce communication barriers in some instances. Summarising the evidence from several studies of the experiences of disabled people from ethnic minority communities, Butt and Mirza state:

The fact that major surveys of the experience of disability persist in hardly mentioning the experience of black disabled people should not deter us from appreciating the messages that emerge from existing work. Racism, sexism and disablism intermingle to amplify the need for supportive social care. However these same factors sometimes mean that black disabled people and their carers get a less than adequate service. (1996: 94)

In their study of young black disabled people's experiences and views, Bignall and Butt conclude:

Our interviews revealed that most of these young people did not have the relevant information to help them achieve independence. Hardly any knew of new provisions, such as Direct Payments, which would help with independent living. Most people did not know where to get help or information they wanted, for example, to move into their own place or go to university. (2000: 49)

Problems included language barriers: language is often seen as the main barrier to effective service provision. It is, therefore, assumed that an adequate supply of leaflets and interpreters in appropriate languages would solve the problem. However, communication consists of more than language skills and literacy. The research suggests that even among British born English speaking Asians, there is considerable lack of knowledge of what services are on offer. Research by Banton and Hirsch bear out the findings of previous research. They state:

Communication problems are identified in all work in this area. Such problems are partly to do with language differences, but also arise from the separate lives led by different ethnic groups in our society and the consequent unlikely coincidence of communications about services arising through informal contacts. (2000: 32)

Morris interviewed women with spinal cord injuries. Their most common complaint about health and welfare professionals was their lack of concern with emotional issues. One woman said, 'There is no space allowed for us to express our grief . . . There is often pressure put on us to 'cope' and if we fail to live up to the standard demanded of us we are categorized as a 'problem''

(1989: 24). They reported receiving little or no help in coming to terms with paralysis, and often felt compelled to be jolly and play a particular role: as one woman put it, ' . . . the staff expected you to have a smile on your face all the time' (1989: 24). Some women experienced a need for counseling, and said that the only thing that made life bearable for them in hospital was their relationships with other patients. Many of the women believed that the rehabilitation they received was unnecessarily competitive, sport-orientated, and geared towards men. Others thought that there was too much emphasis on walking and bladder training. Morris states that the majority of women:

. . . found that communication of the vital information about paralysis was poor, that their emotional experience was ignored, that their needs as women were not addressed, and finally they were given little help in planning for the future.

(1989: 33)

Begum (1996) takes institutional discrimination as her basis for analyzing difficulties in the relationship between disabled women and their GPs. She explored physical, communication and attitudinal barriers. Begum found that such barriers deny opportunities to people with impairments and can impede access

to the services women require. Disabled women, for instance, often find that information is withheld from them. One of her respondents explained that she hadn't been told that multiple sclerosis had been diagnosed, yet her husband had been told two years before she was informed. It seems too that the flow of information from disabled people to GPs is liable to distortion and failures. This is, at least in part, due to GPs' responses to impairment. One respondent in the research said: 'Sometimes I find that a GP - particularly one who is only here for a short time and fairly new - is more interested in my sight problem, or my child's sight problem, than in what I've come to ask about' (1996: 183-4).

Age can also be a factor that distorts communication. Olwen (interviewed by French et al) talking about the attitude of professionals to her loss of sight said, 'Even though I'm older they were 'at your age what can you expect?'. You know they talk to you like that.' (1997:35) Davis (1998) found that, although 90% of visually impaired people are over 60, only one percent of the targets set for visually impaired people by Social Service Departments concerned older people. Henwood makes the point that:

Services for people with disabilities have been a low priority over many years, and the inadequacy of provision – both in quantity and in quality – is well known. Older people are particularly disadvantaged by this situation because of their greater likelihood of disability (1993:113)

Disabled professionals stand in an interesting position in an analysis of communication between professionals and disabled people. It can be argued both that the barriers to communication have discriminated against disabled people wishing to be service providers and also that the acceptance of more disabled people into the professions would be a significant factor in developing inclusive communication. A visually impaired physiotherapist interviewed by French (2001) spoke of poor communication with her colleagues:

I'm a registered blind person but they haven't got a clue.....If I stay in one building I'm fine, it's only when I go over to G... that I get really lost....and one of the physios says, 'So you're not talking today!' because I've walked right passed them.....and I've worked with them for years; oh dear....I just say 'I didn't see you' but they don't seem to learn.

Other health professionals have spoken of the advantages they have when communicating with ill and disabled clients. A disabled doctor explains:

Very many people have told me they can talk to me because I know what it feels like to have an illness. Once you get over that hump of being accepted for training then you can use your disability. (French 1988:178)

Towards Inclusive Communication

Barton states that:

.....the notion of inclusivity is a radical one in that it places the welfare of all citizens at the centre of consideration. It seeks to engage with the question of belonging and solidarity and simultaneously recognises the importance of the politics of difference (1998:84)

‘Inclusion’ has been seen by many as a process of social change, rather than a particular state (Oliver, 1996) and this can be seen to apply equally to communication and relationships. Oliver and Barnes state that:

....without a vision of how things should and ought to be, it is easy to lose your way and give up in the face of adversity and opposition . . . we all need a world where impairment is

valued and celebrated and all disabling barriers are eradicated. Such a world would be inclusionary for all.

(1998: 102)

To develop this conceptualisation, this vision of an inclusive communication environment, we shall conclude this chapter by tentatively offering some general principles based on our discussion.

1. Participation

Priority needs to be given to the participation of disabled people in the planning and evaluation of changing policy, provision and practice in developing inclusive communication. The onus is on service providers to face the challenges of enabling true participation of disabled people in decision-making processes, recognising that disabled people wish to participate in different ways. These include the democratic representation of the views of organisations of disabled people. Participation also includes as wide a consultation process as possible. Disabled people often continue to be treated as passively dependent on the expertise of others yet control seems to have become increasingly central to social change for disabled people.

Users should have more power. Until you give users real power, real control we'll get nowhere.....there's an awful lot of people with a lot of vested interests.....I'd like to see therapy training following the social model rather than the medical model. The only way to do it is to get much more input from disabled people into the training. (From French, forthcoming)

2. Accessible communication

Much is known about the accessibility of information based on the views expressed by disabled people. Clark (2002) offers wide ranging recommendations which cover such areas as: alternative formats (e.g. 'the following formats should be available – large print, large print with pictures and symbols, Braille, computerdisc containing the file in plain text format, accessible website, audiotape, videotape with plain, spoken language, audio description and British Sign Language'). (2002: 62) Suggestions are also made for plain written language; typeface and font size; signage; layout; and websites.

For some people, particularly those with communication disabilities the issue of time can be crucial to a inclusive communication environment. For people with communication disabilities a slower

tempo can be the only accessible pace to ensure understanding.

A participant within the research by McKnight et al explain:

I prefer to speak for myself and I would rather repeat myself several times than have someone say they understood me when they did not. (2002: 17)

Along similar lines, Pound and Hewitt (forthcoming) emphasise that access in meetings will require attention to their length and timing.

Ford emphasises the need for people with speech impairments to have the communication equipment they require and hopes that Article 10 of the Human Rights Act (1998) (freedom of expression) will cover this requirement. He states:

Everyone has things to say and choices to make. In a democratic country people have freedom to express themselves. Speech-impaired people have a right to communicate in the same way as non-disabled people. If we want a society in which disabled people are as valued as non-disabled people, society must ensure that disabled people have the appropriate equipment to be able to communicate.

Ensuring accessibility of information to disabled people is complex and must fully involve disabled people at every stage of the process. This philosophy was central to the research by Parr et al (funded by the Joseph Rowntree Foundation) where an accessible book *The Aphasia Handbook* was produced.

3. Diversity and flexibility

A disabled client (in French, forthcoming) provides the foundation for this by questioning the focus on 'normality', rather than being flexible and taking the client's perspective into account.

What concerns me most of all is this focus on trying to make me 'normal'. I get that from all the therapists. I get a lot of referrals of 'this may help' and 'that may help'. They had a massive case conference before the adaptations - it was a case of 'how normal can we make her first? Are the adaptations necessary?'

The lists of recommendations for communication access, as produced by Clark (2002) and others, clearly challenge the imperatives of normality and emphasise the diversity of communication styles and formats. Nevertheless, there are diverse needs even within specific groups of people with impairments, which again puts the emphasis on listening to

disabled people and allowing them to take control. People with visual impairments, for example, are frequently presented with large print even though the depth, font and colour contrast may be more important. There is also the danger of assuming a disabled person prefers the use of technical adaptations rather than human assistance. As a visually impaired physiotherapist explains:

I'm lucky that the helpers, and all the staff generally, help with all the extra bits of paper that are around. The truth of the matter is, that as a blind person, you could get involved in form filling by putting it on the computer, but what the hell's the point because it's going to take an awful lot of time.'

(French 2001: 128)

There are, of course, many broad social factors to consider in any discussion of the diverse needs of disabled people. As Dominelli argues, for instance, 'translation services should be publicly funded and provide interpreters matched to clients' ethnic grouping, language, religion, class and gender' (1997: 107).

Issues concerning funding are also emphasised by Ford:

Speech impaired people are being denied their fundamental human right to communicate for want of an efficient and properly resourced service. Despite having been

professionally assessed as needing equipment, disabled people are not getting the devices they need from statutory organisations. Education says, 'It is a health responsibility', health says, 'Ask a charity'.....New investment for equipment and training is required as a matter of urgency (2000:6)

This begs the questions, however, of the need for professional involvement in the allocation of such equipment and whether professionals need disabled people more than disabled people need them. As Davis states:

.....those of us who are familiar with some of the history of the disabled people's movement will recognise that today's 'disability professionals' are on a career path that has been carefully and painstakingly carved out by generations of their predecessors. Our movement's long campaign to redefine disability has left little room for doubt that society has been constructed by able-bodied people in ways which serve and perpetuate their own interests. Yet these people have used our consequential marginalization and dependence not as a starting-point for developing with us a struggle for social change and equal opportunities, but as a handy and convenient way to

justify the development of all the inappropriate disability services with which we are now so familiar. (1993:198-199)

4. Human relations

Communication is constructed and embedded in relationships between people. The notion of personal relationships can be seen as irrevocably intertwined with communication. Communication is a means of expressing a relationship; it constitutes the initiation, maintenance and ending of a relationship; and it is the medium and substance through which the relationship is defined and given meaning. A disabled client offered advice to therapists on the basis of her experience:

Forget you're a therapist – just be yourself. I don't mean forget all your training - but be yourself. Don't be afraid of showing the real you because that's what makes people respond, when they're ill they respond more easily if the therapist is being real. (French, forthcoming)

5. Use of inclusive language

In part inclusion reflects the idea that language controls or constructs thinking. Sexism, ageism, homophobia, racism and disablism are framed within the very language we use. This has been characterised and degraded by some people as 'political correctness' (PC), often with reference to examples seem as trivial

or fatuous (e.g. being criticised for offering black or white coffee). Use of language, however, is not simply about the legitimacy of words or phrases – what we are allowed to say or not say. As Thompson (1998) explains, language is a powerful vehicle within interactions between health and social care professionals and clients. He identifies a number of key issues:

- Jargon – the use of specialized language, creating barriers and mystification and reinforcing power differences
- Stereotypes – terms used to categorise people that reinforce erroneous presumptions e.g. disabled people as ‘sufferers’ or as having ‘special’ needs.
- Stigma – terms that are derogatory and insulting e.g. ‘mentally handicapped’ and ‘short sighted’ (meaning lack of insight).
- Exclusion – terms that exclude, overlook or marginalise certain groups e.g. the term ‘Christian name’
- Depersonalisation – terms that are reductionist and dehumanising e.g. ‘the elderly’, ‘the disabled’ and even ‘CPs’ (to denote people with cerebral palsy)

In this light, questions of the use of language go well beyond listing acceptable and unacceptable words to examining ways of thinking that rationalise, legitimise and underline unequal therapist-client power relations.

Conclusion

It is clear from this chapter that disabled people have had much to say about the ways in which health and professional care workers communicate with them. We shall conclude this chapter with three

quotations (French, forthcoming) from disabled people who have valued their contact with health and social care workers:

When I gave up work, and I was very, very involved in my work, my GP referred me to occupational therapy to try and get me to come to terms with it. They were very helpful.

We set up a plan together. I was filling my time with hobbies and I was driven to finish every single task all the time just as if I was at work. We explored that together.....They seemed to understand what I was feeling and we made very small goals. I kept a diary that we explored and worked from. It was very positive and made a bit difference.

She said 'Come in when you like and use all the equipment'.

I was particularly lucky with my physio because she had the foresight that that was what I needed for my recovery – to be in control.....She treated me like a person, she spoke to me like a person and not a patient. I felt in control and that gave me more confidence in myself.....and she understood that.

I liked my speech therapist....and I remember thinking, 'What a fantastic woman, what a fantastic job'....she showed kindness, kindness is something that is not acknowledged enough. She was gentle and empathetic, I felt as if she was joining in with my struggle.

The development of inclusive communication is a complex process that involves, though goes well beyond, active listening. However, as Proud and Hewitt (forthcoming) state:

It will support people with and without language impairment to enrich communication practice, share power and celebrate the creativity and challenge of communication difference.

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