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ARE YOU RECEIVING ME?

Hearing and Being Heard: The Challenge of Deafness

Introduction

The challenge

It could be said that the question, “Are you receiving me?” is the heart of the matter for people with deafness, or any form of impaired hearing. It sums up the challenge of communication, and as a consequence relationships and quality of life, for those who are afflicted with hearing loss and those who share their lives; both closely –family, friends, colleagues, teachers, etc., and more remotely – providers of public information, entertainment, and so on.

At first glance, “Are you receiving me?” looks like a question that applies to the speaker; whether an individual in conversation, a fellow party-goer, announcer, music maker, teacher, whatever. And it certainly is. It is a question that too often is not asked; or is not taken sufficiently seriously, or reflected upon at all deeply. Or worse still, a question that is treated with annoyance or intolerance, or simply ignored.

But it is also a question to be asked by the person with hearing loss themselves. A question to be asked by them of others who share their lives; when it might be rephrased as “Are you *perceiving* me?” – “How perceptive are you of who I am; what it is like to be me; what my difficulties are, my aspirations, my gifts, my potential?” – “How perceptive are you of the *person* who happens to be deaf?” And a question to be asked by them *of* themselves: “To what extent do my attitude my behaviour, my expectations, affect the people I communicate with?”

These challenges, these questions, are too little discussed, and too little understood by people on either side of the deafness ‘divide’.

These notes are intended to clarify the questions, open up the discussion, encourage better awareness of the challenges of deafness; and remedy the negativity that can afflict both the hard of hearing themselves and those who share their lives. They are based on the experience of someone who has been profoundly deaf since the age of three, and who has not only

struggled to live with and overcome that disability; but whose career in electronics has been largely devoted to helping both deaf people and others to understand it and cope with it. Helping to cope has included the provision of technical aids to make this possible; not only by making it easier for deaf people to hear, but in helping hearing people to experience what it is like to suffer from impaired hearing. This experience, learning and expertise has been 'filtered', so to speak, through the ears of friends and colleagues in many hours of conversation, who have tried to do justice to his insights and his passion to the life of people with hearing loss and all who share the challenge to hear and be heard.

"I am who I am"

Everyone is influenced, shaped, and to some extent restricted by the circumstances of their lives, which often include some disability. This may affect the way we see ourselves. Unfortunately, this may also affect the way we are perceived by others, which may be to our disadvantage. At its worst it may amount to a stigma. People with impaired hearing are not alone in this predicament. But the affirmation, "I am what I am", will be difficult for them to make in their own way, in the face of their particular disability. It is an affirmation of our unique value and significance that all of us need to be able to make, whatever our circumstances in life. And it is an affirmation that deaf people must be able and be encouraged, to make for themselves; and that is evident in the attitude of others towards them. This is perhaps the starting point of any project to enrich the lives of people with hearing loss. And it must begin very early in life if this is a child.

Expectations

The scope and limitations of technology. Demonstrating the actual experience of the hearing impaired to the normally hearing.

Most people with hearing loss gain significant benefit from hearing aids. But many of them, many of the people who share their lives, and what is more, many professionals, have false expectations of just how much improvement aids can achieve. The volume of sound may be greater, but its clarity, and the performance of an aid in different circumstances may be far from perfect. False expectations will add to the frustration of living with an aid, and can actually complicate life for the wearer and others around them.

Any aid, for any disability, will be most effective if the user clearly understands how to use it well and what its limitations are; and if others share this understanding. This requires appropriate explanation, encouragement, education, and perhaps training. This of course

applies to aids for hearing disability, but is not always provided or adequate. Where professionals and providers of aids are themselves insufficiently aware of the challenges, there is obviously a problem.

It is always true that we cannot fully appreciate what it is like to be the person who has an illness or a disability, because however empathetic we may be we cannot fully enter into their experience. But one of the objects of the project that this book accompanies is to remedy that lack of knowledge as far as possible. This will be achieved by creating software that demonstrates the experience of people with hearing loss, with and without an aid, and in different circumstances, compared with 'normal' hearing.

Context and environment

The physical and social environment. The circumstances. The event. Background noise, etc.

It seems obvious, but it is surprising how little awareness there is of the effect of environment and context on the ability to hear and the effectiveness of a hearing aid to assist hearing. Background noise - the conversation of others in the vicinity, music, traffic, even the noise of the wind and the weather, will interfere to some extent, and may overwhelm what is heard. This may be by masking the sound, by competing with it, or by distracting the attention of the listener. These things can interfere with anyone's attempt to hear; but so much more so for someone who is already hard of hearing.

This is at best frustrating, and can result in confusion, distress or anger. Even when it is well tolerated, the effort involved to pay attention, to concentrate on what is being said, played, or whatever, can be very tiring; limiting the person's ability to sustain their concentration, to engage with what they are listening to; to learn, or to contribute to discussions; and possibly affecting their energy and wellbeing after the event.

Loop systems in public places are intended to help to overcome this problem. But they need to be installed in the first place, and efficient. And users of aids need to know they are available, and how to adjust the aid accordingly. Organisers and leaders of groups and meetings need to be better aware of the difficulties caused by deafness in those contexts, and of the technology such as table-top microphones available to overcome them.

Communication and conversation

Distance/closeness. 'Visibility'. Intelligibility.

The way that other people engage with someone with hearing loss is another crucial factor determining the ability to hear. Any increase in distance between them; any turning away

during conversation; anything that prevents the listener watching the speaker's face; any indistinctness of speech; will make it more difficult to hear.

Even with normal hearing, what we hear is partly dependant on the context and flow of the conversation, affecting what we expect to hear and how we interpret what we hear or think we hear. A person with hearing loss is in difficulty if he or she cannot make use of these 'cues'.

But in addition, although some deaf people may be glad to disguise their deafness, some modern hearing aids are so small, and so tucked away within the ear that the speaker may not be aware of the disability in the person they are speaking to.

Psychological and social issues

Adult/child 'transactions'. Emotional/social deprivation. Disappointment, being let down, the 'broken heart'.

It is already obvious from these notes that the consequences of deafness for the quality of personal life, working life, and relationships for the sufferer and for those who share their lives can be considerable. The quality of communication between the deaf person and others can make or mar the relationship and the life of the individual; particularly in childhood, when a positive or negative pattern for life may be established. The need to foster a positive emotional state in the sufferer is paramount.

Anger, impatience, frustration, intolerance, misunderstanding can blight the life of a deaf person, and their relationship with those around them when insight, understanding, compassion and tolerance are lacking. The way in which others speak to a deaf person, can for example constitute a subtle and often inadvertent form of verbal abuse. Negative feedback will encourage a vicious circle of hurt, self-doubt, disappointment, and perhaps failure.

The disability itself, the way that others regard it and react to it, the restrictions it imposes, can result in emotional and social deprivation, and affect aspiration and the fulfilment of potential, in a way that becomes a disability in itself.

The role of professionals and experts

Many professionals involved with the hard of hearing in various roles, medical, social, educational, may have little or no idea of what it is like to hear or not hear as their patients/clients/pupils do. They may have limited understanding of the issues discussed in the previous sections of these notes; of how the disability affects everyday life and relationships, self-esteem and aspirations. They may have little insight into what it is like to be 'in their shoes'.

It is an aim of this project to help to remedy these problems, and to equip the professionals to be better able to empathise with and help the deaf people they serve.