HEARING LOSS, TECHNOLOGY and COMMUNITY AT THE START OF THE TWENTY FIRST CENTURY.

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I declare that this thesis is my own account of my research and contains as its main content work that has not previously been submitted for a degree at any tertiary educational institution.

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ABSTRACT

This thesis explores ways in which technology is influencing the lives of hard of hearing people at the start of the 21st century. The thesis develops and is grounded in a distinction between people who referred to as ‘deaf’ and those who are referred to as ‘hard of hearing.’ It is argued that there is a lack of recognition of the special needs of hard of hearing people in deaf and disability discourses and more generally in everyday communication. This lack of recognition is analogous to the absence of women from many forms of social analysis until the latter part of the 20th century. In light of this clearer specification of the people under consideration, attention shifts to a consideration of the various technologies they can access. The context within which these technologies are used is one in which, unlike many deaf people who form an integrated community that is differentiated and separate from the general society, hard of hearing people have tended to become socially isolated within the hearing community. This understanding of the potential for social isolation allows the specific significance of generic computer technology for this group to come to the fore. As a consequence the thesis focuses upon a detailed examination of the place of a hard of hearing online real community in the lives of a number of hard of hearing people.
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Chapter 1: Introduction.

Thesis Aim and Scope

This thesis examines the way in which technology has influenced and enriched the lives of hard of hearing people. Hearing aids and cochlear implants are briefly touched on as these assist daily social exchange. However, I argue that it is computer technology and the Internet that is emerging as an exciting communication technology for hard of hearing people. It is through the personal computer and the Internet that hard of hearing people are able to communicate not just with their families, friends and work colleagues, but also with other hard of hearing people and other people in the broader community. Drawing on the recently established concepts of virtual communities I shall show that the Internet has provided a medium for contact and the establishment of a community previously denied hard of hearing people. This close contact is giving them more self confidence to communicate and subsequently interact beyond their immediate physical environment.

The thesis draws on the work of several prominent sociology theorists. I shall offer an alternative to the commonly held notion that technology is solely related to machinery, engineering and how things work. Bush's (1983) treatment of technology as an equity issue will be presented to support my argument that recent advances in technologies have given hard of hearing people an opportunity for social contact that was not previously available. I shall also use the work of several recent theorists to examine the extent that hard of hearing people are forming online communities.
In this chapter, by way of introduction, I briefly describe and explore several areas related to hearing loss:

- Statistics relevant to hearing loss in the Western World.
- An outline of hearing loss to eliminate some of the confusion that may exist in our understanding of the differences between deafness and other forms of hearing loss.
- Similarities and differences between people who are born with little or no hearing and people who develop a hearing loss after learning to speak with a particular focus on the social difficulties experienced by people with the latter condition.

Following these summaries I shall show similarities between the historical exclusion of women from sociological discourse as argued by Dorothy Smith (1987) and the historical exclusion of hard of hearing people from deaf discourse and its further exclusion from disability discourse.

The chapter concludes with an outline of the structure of the thesis.

**Hearing Loss: Statistics in the Western World**

Australia, Britain and the USA show similarities in hearing loss statistics, with no clearer breakdown of the figures available than those shown below. A South Australian study found that over 22% of the population over 15 years of age had some measurable hearing loss. A breakdown of the figures into age groups showed that 5.2% of the population had a loss between the ages of 15–50 years, 28.3% between the ages of 51–60 years, 58.7% between the ages of 61–70 years and 73.5% over 71 years. Figures from a British study lead researchers to conclude “the corroboration of the two studies reinforces the status of hearing impairment as the most common disability of adulthood” (Wilson et al. 1999). Similar figures have also been obtained in
the USA (Howe 1993; Kampfe & Smith 1998). Hearing loss also varies in severity. As Luey, Glass and Elliott (1995:1) state, “only 1% of the population is profoundly deaf, and of those, only 22 % (0.22 percent of the whole population) lost their hearing before age 19”. These figures show the very small percentage of people in these western countries who were born deaf, and that there is a much higher chance of acquiring a hearing loss after age 50. The major difference between the two groups of people is that the majority of people in the former group did not learn to speak effectively and rely predominantly on sign language to communicate. Those in the latter and larger group, use the spoken language with a small number learning sign language later in life. While they can speak, they cannot converse well because their hearing loss impedes spontaneity. In many cases, and certainly for people with a profound loss, there may be little difference in the level of hearing loss between people in each group. However, the distinction between those who are born deaf and those who lose their hearing later in life is crucial to this thesis.

**Hearing and the Medical Condition of Hearing Loss**

A detailed anatomical, biological or medical analysis of deafness is not the concern of this thesis. However a brief outline of the anatomy of the ear, including some of the types, causes, measurement and classification of hearing loss does assist in understanding the social issues and consequences of this disability. What is commonly described as the ear is only one of three interconnected anatomical parts that trap, conduct and convert sound energy into electrical energy for transmission to, and interpretation by the brain. The first of these anatomical structures is the visible outer ear and ear canal. These act to catch sound waves, similar to how a hand can catch a ball. The sound passes down the ear canal and causes the ear drum to vibrate, which in turn activates three interconnected microscopic bones in the middle ear. These vibrations then act on a small membrane that separates the middle from the inner ear. Once these vibrations reach the inner ear, physiological and biochemical
reactions occur in the cochlea and the resulting electrical energy passes along the
acoustic nerve to the brain. Anatomical malformation, disease either by fungus, virus
or bacteria, tumour, genetic predisposition, accident or other trauma such as loud
sounds, drugs, and age deterioration at each or any one of these sites can lead to a
hearing loss. Added to this diversity of causes are the variations in the types of loss.

The sound we hear is transported to us as a stream of energy in the form of air
pressure waves over a range of frequencies. Through chemical change the sound
energy reaches the brain, which then interprets these reactions into meanings. Hearing
loss is the condition that occurs when the brain does not receive some, or all, of these
frequencies. Some people may lose high frequencies, which could mean they do not
hear sibilant sounds. Others may lose only low frequencies, whilst still hearing the
higher frequencies. People with these types of loss may be misunderstood and
accused of faking their hearing loss. Such phrases as ‘I thought you were deaf’ and
‘He’s only deaf when he wants to be’ can be very hurtful and frustrating for people who
have been able to hear clearly in the past, as they are increasingly isolated from social
exchanges by their hearing loss. Other types of hearing loss can involve a larger range
of frequencies. People with this kind of hearing loss will have difficulty hearing all
sounds and in all conditions, even where there is little, or no background noise to mask
certain speech frequencies. Some forms of hearing loss occur gradually over many
years and may go un-detected until the condition is well advanced. For others the
hearing loss may occur rapidly. There is the added complication that hearing loss may
be different in each ear, when both ears are affected. This will result in the affected
hard of hearing person hearing some sounds better on one side than the other, further
confusing the people with whom they converse. Moreover the hearing loss in each ear
may start at different times and progress in different ways. One participant in my study
told how she was born with no ability to hear in one ear and it was not until 17 years
later that she developed a loss in her other ear. Not only is hearing loss a hidden
disability, but its manifestations can be, and frequently are, misinterpreted and misunderstood by hearing people.

The measurement of hearing loss has been revolutionised in recent years by the development of specific audiometric instruments. Not only can a loss of hearing be detected and quantitatively measured, but the type of loss can also be identified and in most cases the cause determined. Furthermore, technology has advanced to the stage whereby all newborn babies can be tested for hearing loss and those “with positive screening tests should be referred for definitive testing and intervention services” (Wrightson 2007: 1). Improved language and communication skills in those affected has yet to be studied, but the programme is being endorsed because of its promise.

Loss of hearing is measured in decibels over the range of frequencies in the audible spectrum. Audiologists classify the deafness as mild, severe, or profound depending on the amplification of the sound signals presented to the ear to restore “normal hearing”. Persons requiring an amplification of 25 decibels are considered to be hearing impaired, 30 - 45 decibels to have a mild loss, at 45 – 60 decibels a moderate loss, at 60 – 75 decibels a severe loss, and a profound loss over 75 decibels. Himber (1989:50) points out from her research, “there is some variation in the precise figures that audiologists use in making a diagnosis.” It must be pointed out that not all people born deaf have a hearing loss in the profound range. Learning to speak effectively requires adequate hearing over the full range of normal hearing frequencies so that the person learning to speak can hear and learn when they are pronouncing the words and phrases properly. Many people born with even a relatively minor deafness will not only be hearing impaired, but they will also often mispronounce some words because they may not have learnt how to pronounce them correctly. In some cases this may result in some relatively inconsequential quaintness in their language, which does not impair
their speech communication. In other cases a hearing impairment or mild loss may lead to ambiguities and misunderstandings in conversations that are frustrating for those involved and worse, can lead to significant misunderstandings. Furthermore, wearing a hearing aid does not give the same positive result as wearing corrective eyeglasses give to a person with reduced eyesight. A hearing aid can only amplify sound and its effectiveness depends on the type and site of the obstruction to the sound waves (NIDCD 2002).

Hearing Loss and Deafness

The generic word “deaf” covers a variety of commonly used terms describing people with hearing loss. These people are variously called hard-of-hearing, late deafened, hearing-impaired, have adult onset hearing loss, are pre or post-lingually deaf, and more recently ‘hearing challenged.’ Researchers, and members of society more generally, consistently fail to differentiate between deaf and hard of hearing people and use any of these descriptions indiscriminately. One view of hearing loss labelling comes from Punch, Creed and Hyde (2005: 2) who say “although ‘hard of hearing’ has often been used to describe people with less than severe hearing loss, its definition is increasingly adopted to include people with degrees of hearing loss whose communication mode is primarily oral-aural and effectively use their residual hearing supplemented by speech reading and assistive hearing devices.” Readers unfamiliar with any or all of these terms may be confused. Consequently for clarity I refer to those people who are born with a significant hearing loss as ‘deaf’, and those who develop a loss after learning to speak as hard of hearing. Moreover, I am reluctant to refer to people with either hearing loss as a ‘deaf person’ or a ‘hard of hearing person’, as this implies that it is the hearing loss that defines that person. However, for brevity I shall from time to time refer to each in that manner.
Communication is a vital part of human social interaction and, for the majority of people, verbal communication predominates. However, to learn to speak effectively with the minimum of effort it is essential to be able to hear from birth (Lynas, Huntington & Tucker 1998:127). Those people who are born with little or no hearing, are the people usually associated with the word ‘deaf’. Many of these people learn to communicate effectively amongst themselves using sign language, or a combination of sign and some learned verbal language (Lane 1999:130). There are many studies of deaf people. Researchers tend to introduce their work by informing the reader that whilst there are many people with a hearing loss, their studies focus on the people who are deaf, dismissing the larger group of people who lose their hearing after learning to speak (Lane 1984:xi; Gregory & Hartley 1997:vi).

A significant difference between deaf and hard of hearing people is their attitude to their hearing loss. People who are born with little or no hearing can be divided into two distinct groups. The first group views itself as a separate cultural minority. The members of this group mainly use sign language to communicate, which is very quick and effective, even in very noisy environments. Their conversations are not overheard by people with normal hearing and they enjoy the benefits of their own silent language within a normal hearing community. They label themselves as deaf and name their culture with a capital ‘D’ as ‘Deaf Culture.’ This group is often referred to as ‘the Deaf community’ just as one refers to particular national or ethnic groups within the broader community. The second group has assimilated into the hearing community and do not view themselves as part of the Deaf culture (Tucker 1997:24-28). Many of these people may have been born to hearing parents who believed that their child would benefit more from learning the difficult task of speech. These people have more in common with hard of hearing people and my research indicates that they too may experience social isolation similar to hard of hearing people. Furthermore, as methods
Loss of hearing, whether great or small, is an invisible handicap affecting their ability to converse effectively with hearing people in most normal situations. Hearing people are often unaware that there is a problem when conversing with hard of hearing people and do not realise that they need to adjust their speech to assist the communication. Furthermore, the invisibility of the condition means that even if the hearing person is aware that they are talking with a hard of hearing person, they are not visibly and continuously reminded of the hearing loss and may lapse into their normal speech with adverse consequences for the communication. Contrast this with people who use a wheelchair because they have lost the use of their legs. It is almost impossible for another person to ignore the wheelchair and the loss of movement when in the presence of the person in a wheelchair. People will make allowances for the person in the wheelchair without a specific request from that person.

Having said that hard of hearing people belong to the mainstream hearing community, it needs to be continually said that their hearing loss, no matter how mild, tends to increase their chances of social isolation. Technologies such as various forms of hearing aid, or cochlear implants in extreme cases of hearing loss, do not restore hearing to normal and this results in a common misunderstanding. People with no hearing loss may believe that these devices restore hearing and thus do not make allowances in their speech when communicating with a hard of hearing person. More often than not the hard of hearing person is the one who apologises for not hearing and may attempt to remedy a difficult exchange by pretending to understand. The outcome for the hard of hearing person is frustration. This misunderstanding can have detrimental effects for adolescent hard of hearing people. Recent research has indicated that “other people’s lack of understanding of their hearing loss constituted the
greatest potential barrier to adolescents’ educational and career goals” (Punch, Creed & Hyde 2005: 1).

At this point in our history, the Internet is emerging with the potential to overcome this isolation. Not surprisingly hard of hearing people have sought out others with this problem through the Internet. Initially a hard of hearing person may be seeking information about hearing loss, which can and does result in discovering others with a hearing loss and a genuine need to communicate. Where a sincere desire to belong to such a group manifests in exchanges based on both frequent online contact and the potential for occasional physical contact, then I shall refer to such groups as “Hard of Hearing Online Real Communities”.

**Social Difficulties Confronting the Hard of Hearing**

Hearing loss increases markedly from age 45 years onwards (Kampfe & Smith 1998:24). Affected people, who have perhaps been contributors to family, work and various small and large social groups, may gradually find that they are being excluded from conversations. Moreover, normal hearing people may also not understand why hard of hearing people do not involve themselves more in group conversations and activities. As suggested by Heine et al. (2002, p. 356) older adults experience ‘communication disruptions which in many instances are not resolved’ and recommend training programmes for these people and their partners. Even a relatively minor hearing loss can result in simple words being mistaken for another of similar sound and/or mouth movement. This can result in an inappropriate response to a question or comment in a conversation. For example, I was recently talking on the telephone to my son in the USA and in the course of the conversation he said that he had just had a slow day. “That’s nice for you to have a rest” I replied. There was a pause and then he said “Not slow, but ‘s’ for Sue, ‘n’ for Norm –snow” – so then we talked of the weather! When these misunderstandings happen repeatedly, over time the hard of hearing
person’s embarrassment is compounded. As a consequence the embarrassment may
result in social isolation and even depression. The workplace also presents many
“deaf and hard-of-hearing workers have reported feeling socially isolated and lonely in
the workplace, experience exclusion from the ‘office chatter’ and social interactions
such as occur during lunch breaks, and missing out on incidental information and
informal conversations.” For those hard of hearing people who may become aware of
their conversational limitations, a new set of barriers must be overcome. For example,
to acknowledge to others that they have heard incorrectly, a decision has then to be
made whether to interrupt, explain and accept a halting conversation. If they did
interrupt, they may find that the topic may have been something as inconsequential as
the weather or the person’s wellbeing. This requires a degree of recognition of their
impairment and a self-confidence to accept the consequences. Eventually, having
acknowledged their hearing problem, the person may seek professional help. Using
the example of deteriorating eyesight once again, when people experience difficulties
with their eyesight they usually have their eyes tested, and as a consequence,
purchase a pair of spectacles. Furthermore, these people will frequently or continually
wear their spectacles without too much hesitation. Similarly, when a person acknowl-
dges that she/he is having difficulty hearing, being tested for, purchasing and
wearing a hearing aid would seem an obvious and logical path to follow. However, as
will be discussed later in the thesis, this is not usually the case. With few exceptions,
people who are hard of hearing do not project themselves publicly, most going to great
lengths to hide their impairment from others. Consequently many of these people can
become alienated from people with no hearing loss and from others like themselves
because of their difficulty in understanding and contributing to verbal communication.
One exception of note in recent times is the hearing loss of John Howard the current
Australian Prime Minister. He was reported saying that he now wears a hearing aid
hidden in his ear where once he wore a bulky one behind the ear (A chord strikes PM.,
2000). His disability has obviously not impaired his capacity to hear and converse with the broader community that is often not forgiving of those who do not hear well and cannot make themselves understood. John Howard was clearly not born with a hearing loss and is for this thesis a member of the hard of hearing group.

Hard of hearing people do not view themselves as being different from the mainstream hearing community of which they are part. Unlike deaf people within the deaf communities, they “rarely join or stay members of organisations composed of hard of hearing people” (Ross: n.d.). I agree with Ross’s observation but suggest that from my experience the real life organisations that are presently available in Australia either come in the form of lip/speech reading classes or periodic social gatherings. While both are valuable and have their place, lip/speech reading can prove very difficult to learn and may cause a further loss of self-esteem for those who cannot master the skill easily. Social gatherings can provide social and emotional support for those who attend, but are not sufficient to make up for the isolation felt by many hard of hearing people in the times between these meetings. Luey, Glass and Elliott (1995:177) say “deafness (sic) is both a disability and a loss; it is something to be mourned.” This mourning process cannot always commence because “deaf (sic) people are rarely encouraged by those around them to give expression to any pain, sadness or anger they are experiencing” (Robertson 1999:37). In contrast deaf people would not experience this sense of loss, as they have never known hearing and experienced the loss. Luey, Glass and Elliott (1995) and Robertson (1999) both use the word ‘deaf’ when they are referring solely to hard of hearing people.

**Social Exclusions**

Canadian sociologist Dorothy Smith argues that historically sociological theory and ideologies were written for men by men (1987:18). She does clarify later that her
method of inquiry is “for people... since it cannot be gender specific” (Smith 1999: 5).

In a review of her argument, and using the study of disability as a subgroup of sociology, I have compared it with the lack of information and theory on hard of hearing people in disability discourse. Following Smith who says that men wrote for men with the exclusion of women; then we could say that disabled people wrote for disabled people including deaf people but with the exclusion of hard of hearing people.

Disability as a separate sociological topic came into being in the 1970's. This was theorised by academics with a variety of disabilities, and other interested theorists, who tended not to differentiate between the multitudes of different disabilities. What little has been written about people with a hearing loss has focused on deaf people and their struggles to define themselves as members of a separate culture. Hard of hearing people, who form the largest group of people with a hearing loss, did not have a voice. They were excluded from both the Deaf culture and disability discourse and consequently from sociological theorizing. They are included in the hearing world because they can speak and maybe hear some meaningful sounds. Whilst the majority of hard of hearing people lose their hearing in later life, this is not always the case. Many young adults and children have suddenly lost all, part, or are progressively losing their hearing after learning to speak and becoming part of the hearing community.

People generally live in a hearing world where contact with others usually takes the form of communicating in words. Our education takes place mainly using spoken words. Entertainment in the form of TV, radio, videos, concerts and other live shows, with the exception of mime, use words or sounds to transmit their various messages. This hearing world may reinforce a hard of hearing person’s isolation because the concentration required to decipher sounds can cause the person to ‘switch off’ mentally due to tiredness. However, because we live in a hearing world and also learn written
words to communicate, technology does provide a medium for non-verbal communication.

In paraphrasing Smith (1987:17-18), I include myself as a hard of hearing person in the following declaration. Because hard of hearing people have been excluded from the making of the ideology of the knowledge of disability, it means that our experience and our interests have not been represented in the organisation of our ruling, or in the development of knowledge that has entered into it. On the other hand, and since the advent of sign language, deaf people have formed part of this knowledge. As a group they are making inroads, albeit in small ways, into structures of influence.

Whilst women have been excluded from the development of knowledge there has been consistent information centred on women to help Smith in formulating her argument. Unlike deaf people who have been referred to intermittently throughout history, reference to, and focus upon, hard of hearing people has not had historical precedents. Hard of hearing people have had a history tied to that of deaf people until the development of sign language 16th century. After that period and until the late 20th century which has seen the advent of assistive technologies and lobby groups, hard of hearing people have been silent about their special needs, preferring to be seen as part of the culture of the hearing world.

Women writers (Wendell 1997; Thomson 1997) who are either part of, or closely aligned with, the disabled people’s movement have spoken about their belief in the importance of feminist ideas for disability theory and politics. However they noted, with profound disappointment, that non-disabled feminists have failed to address the concerns of disabled women, sometimes actively excluding them from participation in feminist events Smith refers to women in general who “have not had, until very recently, access to the educational skills necessary to develop, sustain, and participate in the making of a common culture” (1987: 19). In saying this, Smith has failed to
consider women with disabilities in her arguments. Furthermore, feminist scholars Fine and Asch (1988: 4) say “The popular view of women with disabilities has been one mixed with repugnance. Perceiving disabled women as childlike, helpless, and victimized, non-disabled feminists have severed them from the sisterhood in an effort to advance more powerful, competent, and appealing female icons.”

Nowhere are disabled, deaf or hard of hearing women referred to in classical feminist literature, leaving it to later disabled feminists to theorise their situation. However it can be safely assumed that these people may also have lacked necessary skills, which combined with their impairment would have left them further isolated. Perhaps it is also safe to say that deaf and hard of hearing women would have been of a lesser status again than their male deaf or hard of hearing counterparts.

Notwithstanding, Smith refers to “the discovery of a point of rupture in my/our experience as woman/women within the social forms of consciousness” (1987:49). Similarly I see a fracture in the consciousness of hard of hearing people from the social consciousness of deaf people. This social consciousness partly manufactured by the ruling institutions, which in Australia are the various state organisations, categorises deaf people and subsumes hard of hearing people within that category, or excludes hard of hearing people altogether.

**Structure of the Thesis**

Having given an overview of hearing loss, in chapter two the thesis will show how throughout history the hard of hearing people have not been recognised as separate from deaf people. Chapter two will also briefly explore the history of hearing technologies with special reference to 20th century innovations. Chapter three will review theoretical perspectives that argue in favour of locating hearing loss as an independent discourse. These accounts set the scene for later analysis. As the main
aim of the thesis is to show a nascent hard of hearing community, chapter four provides an overview of theoretical perspectives conceptualizing community from its historical beginnings to present day theories of the virtual community. Chapter five outlines the methodology used, incorporating a brief outline of some feminist interview techniques and aspects of online interviewing. In chapter six I present several personal stories sent via e-mail, and examples of interviews undertaken in person. The remainder of the chapter shows how two different groups of hard of hearing people utilise technology, and behave, in large gatherings. These groups are communities of that are forming as a direct result of late twentieth century technologies. After discussing several aspects discovered from my communications with the participants, the thesis then concludes that the concept of ‘virtual community’ offered by some modern theorists does not of itself fulfil the criteria I would stipulate for an online hard of hearing community. Many of the people involved in these groups concur that without some form of visual contact many of these people would relinquish their membership. Consequently I prefer the description ‘Hard of Hearing Online Real Community’ to recognise recently formed hard of hearing communities.
Chapter 2:

A Brief History of Hearing Loss and of Hearing Technologies

History of Hearing Loss

Almost all of the recorded knowledge of hearing loss is concerned with deafness, that is, with people who were born deaf. It would have perhaps been the lack of speech development in early childhood that would have drawn attention to their condition. From my extensive research, the history of acquired hearing loss is not written, and the history of deafness does not appear until the 16th century. There is however some historical evidence of assistive hearing technologies being manufactured during the 18th and 19th centuries for some people with hearing loss. This confirms that hearing loss was recognised, as people endeavoured to obtain tools to continue social exchanges as members of the mainstream hearing community. It is necessary to look to the history of disability to glean information on deafness, and from that draw conclusions concerning acquired hearing loss.

There is some evidence from antiquity of how the community, as we know it, considered disability. Stiker (1997:39) reminds us that the Western culture was and is strongly influenced historically by Judaic, Greek and Roman antiquity. There is mention of deafness in the bible. According to early pre-Christian Jewish texts “the deaf and mute are considered subnormal”. In a later period, the writings of the Qumran community show that the deaf were considered impure and on those grounds were excluded from religious ceremonies (Stiker 1997:24-25). It is unknown how those people with an acquired hearing loss may have been labelled by this culture. It is possible that their exclusion would have come later in their life as their hearing loss progressed. Furthermore, what records have survived would probably have referred solely to the Greek and Roman aristocracy. For example, the first deaf person named
in history was the grandson of a Roman consul. Also, Hadrian the first century AD Roman emperor “was so ‘deaf’ (i.e. in my view, hard of hearing) that he had to cup his hand behind his ear, even while riding into battle” (Earliest Known Deaf People to 1700): [online] n.d.). On the other hand the fate of the common people and slaves, whose daily life would have been one of toil, was probably considered to be of little or no consequence and was not worth mentioning by the people in power. It is recorded that in Sparta and early Rome the practice was one of exposing deformed infants to the elements to hasten their death. Stiker points out that people with a sensory loss were not considered a source of terror as were those born with a physical malformation (Stiker 1997:41). However, it is just as possible that if sensory loss was as manifest at birth as physical deformity, then maybe those afflicted babies would also have been left to die.

Pre Christian Europe may have been a place where its inhabitants survived the best they could. Perhaps the small communities were similar to some of the tribal practices of third world countries where any person capable of working had to work not only for their own survival, but also for that of the community. Verbal skills may well have been limited and social conversation of less importance than it is in today’s western societies.

Christian thought, as evidenced from the New Testament, introduces the old Judaic culture to the view that “the question is no longer whether you are purified but whether you have a pure heart” (Stiker 1997: 34). In other words there is the introduction of the concepts of good and evil. A ‘good’ person, no doubt judged by their deeds in life, would have been one with ‘pure heart’. A person who was deaf, but had followed Christian tenets, would not have been excluded from a Christian community and there is evidence that during this period the Christian belief in charity was manifested in help for the blind and those too ill or infirm to work. Stiker (1997:25) also draws attention to
the different treatment in Islam as evidenced from the Koran, where the disabled are treated as incapable through no fault of their own, but still excluded from ritual ceremonies.

Through the Dark Ages and into the Middle Ages most of the population worked and lived in rural areas and it was probably less important that a person could hear and speak properly. It would have been their ability to perform the necessary manual tasks that was critical. Furthermore, in the Middle Ages for those children born with a hearing loss who did survive, it is probable that the following observation of the inhabitants of a Congolese village might have relevance,

Nobody cares that she’s bad on one whole side because they’ve all got their own handicap children or mama with no feet, or their eye put out. When you look out the door, why, there goes somebody with something missing off of them and not even embarrassed of it. They’ll wave a stump if they’ve got one, in a friendly way (Kingsolver 2000:61).

Although the above is quoted from fiction, the memories are those of the author. Stiker (1997:65) who comments that literature of the Middle Ages is almost devoid of references to disability and deafness presents a similar view,

We only talk about those not present. In other words if the historical account is so brief, it is perhaps because the disabled, the impaired, the chronically ill were spontaneously part of the world and of a society that was accepted as being multifaceted, diversified, disparate. Normality was a hodge-podge, and no one was concerned with segregation, for it was only natural that there should be malformations.

Davis (1995:9) has also reached a similar conclusion,

The fact that we do not know this history of disability, that the record has never taken note of these impairments, shows us, perhaps, that such
differences were not, by definition, memorable. Or if they were memorable were not seen as impairing function.

I would interpret Davis’s ‘function’ to mean the ability to do manual work, as this was crucial for survival in pre welfare times.

Prior to the Industrial Revolution home industries provided the fabric for clothes. Just as women played an active role in manufacture during those years, so too would any person capable of working. Hard of hearing people would similarly have been employed, as many of these tasks would not have required much verbal communication.

Between the late 16th and early 18th centuries the first attempts were made in England and several European countries to teach deaf people to communicate using sign language, lip reading, or drawings, (Stiker 1997:106). However, there is no record of those common people who developed a hearing loss after learning to speak, no matter how profound their loss. Just as in the Middle Ages, people suffering deafness and hearing loss would have already been employed on tasks that did not require acute hearing and their loss would have gone unrecorded.

In contrast, there are records of aristocrats and wealthy individuals with hearing loss during that period. Pierre de Ronsard, a renowned French poet served as a page to a French prince. He developed a hearing loss when he was sixteen, and probably as a result of his education and social connections, was able to transfer his feelings into poetry (Earliest Known Deaf People (to 1700 AD): [online] n.d.). Jonathan Swift a writer of note during that period was losing his hearing and wrote of his feelings:

On His Own Deafness

Deaf, giddy, helpless, left alone,
To all my Friends a Burthen grown,
No more I hear my Church's Bell,
I hardly hear a Woman's Clack. (Deafness [online] n.d.)

The eighteenth century Spanish artist Goya became “deaf, old, slow…” (Hagen 2003). The term ‘deaf’ may have been a mild or severe hearing loss which today would probably be remedied with a hearing aid. It is worth noting that the house where Goya lived became aptly named “Quinta del sordo” or “Country house of the Deaf Man” (Hagen, [online] 2003). This suggests that to be deaf at that time may have been a burden but not a great stigma. Once again, I suggest that the word ‘deaf’ would refer to ‘hard of hearing,’ as to have been born deaf in those days would probably have meant that the person may not have had the means to own a house.

Whilst there is no reference to the poet Ann Taylor (1782-1866) having hearing difficulties, she wrote of hearing loss in old age:

Deaf Martha

Poor Martha is old, and her hair is turn’d grey,
And her hearing has left her for many a year;
Ten to one if she knows what it is that you say,
Though she puts her poor wither’d hand close to her Ear.

(A Celebration of Women Writers [online] n.d.).

One notable record of hearing loss in this period is that of the composer Beethoven. It could be concluded from the absence of other records that he was one of the very few people with acquired deafness of the time. However, he is remembered because of his prodigious musical genius, not because of his hearing loss.
The Industrial Revolution caused a shift from cottage industries in rural areas to town and city based employment in purpose built manufacturing plants. The poor and young would still have been employed in labour intensive industries, and for hearing people working in heavy industry there would have been a constant exposure to very loud noise, one of the contributing factors to hearing loss. This change in employment was the beginning of the discrimination and stigma that has marginalised both deaf and hard of hearing people in those communities.

The study of science and the resulting technology was a major fascination in 19th century Britain and Europe. Institutions were developed for the blind and deaf as places where work and communication skills could be taught. The rehabilitation of these people with sensory impairments set them apart from people with other disabilities (Stiker 1997:108), but there was still no recognition of people who were hard of hearing. These were the people who would have struggled to maintain their place in the workforce knowing the very serious economic and social consequences of becoming unemployed in a society that did not embrace welfare for the disabled. For those people who gained acceptance and social position before losing their hearing, just like the hard of hearing people today, there would have been common behavioural ploys, such as pretending to hear, to prevent detection.

At this time there was an interest in statistics and record keeping. The words ‘normal’, ‘norm’, ‘normality’, and ‘normalcy’ in relation to the average person first appeared in the European languages in the mid 19th century (Davies 1995:24). It followed from this shift in thinking that any person who could be viewed as other than normal was considered deviant. People born deaf and who used sign language to communicate would have been seen as deviant, whereas those who had developed a hearing loss after learning speech would have been better able to hide their disability. In the late 19th century there would have been an added motivation for people to hide their
hearing loss. The combination of Darwin's theory of evolution with the new word ‘eugenics’ and what that implied, meant there was a push to eliminate the people who did not fit the norm. The reasoning was that by doing this, ‘normal’ people would eventually breed ‘normal’ children and the others would disappear. As has been pointed out, “eugenics became obsessed with the elimination of ‘defectives,’ a category which included the ‘feebleminded, the deaf, the blind, the physically defective’ ” (Davies 1995:31).

Well into the 20th century, deaf people were institutionalised and encouraged to learn to use verbal language, whilst communicating very effectively amongst themselves using sign language. Once they left school they joined communities where the only method of communicating was by signing. These people argued that sign language was comparable to the languages that distinguished other cultural groups and consequently did not regard themselves as disabled. From the mid 20th century marginalised groups found their voice through social movements such as the Feminist Movement, the Disability Movement and the Deaf Culture, and were well established by the end of the 1970’s.

Hard of hearing people on the other hand did not know and use sign language, had developed relationships with hearing people and did not belong to the deaf cultural group. Neither were they well represented in the Disability Movement. The single most significant reason for this lack of representation is that the institutionalised practices of society were, and are still based on the unquestioned premise that the ability to hear speech is a given. Unlike the feminist push for recognition, hard of hearing people were silent. Unlike the deaf people’s insistence on their separate Deaf Culture, hard of hearing people remained silent. Unlike the Disability Movement’s political campaigns, there was silence from the hard of hearing people. Hearing loss, however it is acquired is hidden. However, sign language is visible and in a hearing
culture the condition of deafness equates to people who use sign language and do not speak verbally. Hence interpreters who can both hear and sign may be provided to translate for deaf people in situations, such as a courtroom, where the institutionalized mode of communication is used. Similarly the Telephone Typewriter (TTY) is available for deaf people and for hard of hearing people with a profound hearing loss. Apart from the advertisements for hearing aids found in local newspapers, and the occasional flyer in the doctor’s surgery, there is very little public information about hearing loss readily available for the majority of people who are hard of hearing. Paraphrasing Smith (1987:35) who says, “we need also to learn how to treat what other women say as a source and basis for our own work and thinking. We need to learn to treat one another as the authoritative speakers of our experience and concerns.” We could very easily say, “we need also to learn how to treat what other hard of hearing people say as a source and basis for our own work and thinking. We need to learn to treat one another as the authoritative speakers of our experience and concerns.”

At the start of the 21st century, representatives of hard of hearing and deaf people are now lobbying governments for improved services. For example, in Australia the Deafness Forum is the premier lobby group representing various national hard of hearing and deafness related organisations. These include, Better Hearing Australia Inc. (BHA), formed principally to teach lipreading techniques, and Self Help for the Hard of Hearing Inc. (SHHH), an information and socially orientated organisation. More recently, CICADA, a social and information organisation has formed for people with cochlear implants. These organisations have been formed either by parents as in BHA in Western Australia in 1950’s, or by professionals and hard of hearing people as in SHHH and CICADA. BHA, which had its origins in Victoria in 1932, has branches in all states. On the other hand, SHHH formed in the 1980’s has branches only in New South Wales and Victoria. It is noteworthy that hard of hearing people did not form these groups without the support of parents or audiologists, suggesting that hearing
loss may also lead to a diminished sense of self worth and confidence. As all of these organisations rely on donations, limited government funding, member subscriptions and volunteers to operate, the available information distributed by them is understandably limited. Consequently membership, as a percentage of the population of hard of hearing people, is small. There are similar organisations operating in many European countries including Finland, Japan and the USA.

Legislation and social networking are only part of the process and environment that contributes to the continued participation of hard of hearing people in the hearing world. The other substantial contributor is technology, without which the social hearing-linked interactions of many of these people would be impossible. In the following section I will identify the role that technology has and continues to play in the lives of people with an acquired hearing loss.

**Development of Hearing Technologies**

The Macquarie Dictionary defines technology as “the branch of knowledge that deals with science and engineering, or its practice, as applied to industry; applied science” (1981:1775). A definition that implies a more sociological focus, although meaning the same as the Macquarie reference is “the practical application of knowledge and use of techniques in productive activities” (Jary & Jary 1991:651).

Although historical records show that animal horns and later wood and metal were fashioned into ear trumpets the first record of any useful manufactured hearing aid technology came in the 1800s with the introduction of pre-electric horns and trumpets. These were followed from 1899 to the 1940’s by the carbon electrode hearing aids. These used a large 3v or 6v battery but could only be beneficial for people with a moderate hearing loss. Vacuum tubes followed by transistor or electronic hearing aids
were developed and manufactured between the 1920’s and 1950’s. By 1953 transistors had replaced the vacuum tube devices, and the development of various models occurred because the size of the aid could be significantly reduced. Digital and analogue circuits were researched from 1982, and in 1996 the first fully digital behind the ear hearing aids were produced in commercial quantities (Starkey Labs [online] 2003).

Various other technologies have been developed to provide assistance for hard of hearing people to allow them to live independent lives. Strobe lights can be installed in dwellings, replacing the standard security alarm systems available for hearing people. These can also be attached to a doorbell and fire alarm. Vibrating alarm clocks that clip onto a pillow or bed sheet are useful for those people who cannot rely on sound to wake them up, whilst TTY and Voice Carry Over phones are available for people with a profound hearing loss. Technologies also extend to the realm of medicine, where surgical techniques have improved the hearing, or speech recognition, for many hard of hearing people. These technologies include the conception, design and manufacture of innumerable instruments and devices ranging from simple prostheses to complex electronic microscopic apparatus for cochlear implants.

It is a common experience for those who have lived through the last 50 years of the 20th century that technology has created some remarkable results. Computer technology has changed our lives forever. Technicians and scientists have been perfecting the cochlear implant technology since the 1970s, and in 1982 whilst it was still some years away from relatively comfortable use, predictions were being made “micro-technologies will assist …the deaf to hear” (Jones 1982: 42). However, just as women with prams found a use for wheelchair ramps, so too have hard of hearing people found another use for computers. Through Internet communication they have discovered that they are not alone. Immediate access to information and support is
available at any time. Where they may have become socially isolated, they now have found new friends. In the Internet group that I discovered, conversation topics are varied and no one is excluded because of lack of hearing. It is a site where I found that I could appreciate a joke’s punch line instead of only acting as if I had heard.

Hearing aid technology is designed for a large range of hearing losses, but according to research conducted in the USA it is remarkably underutilized (Kochkin 1998). On the other hand cochlear implants are specifically designed for people with a profound hearing loss. In other words cochlear implant technology is extremely user specific. Computer technology is universally available and can and has been adopted by many people including those with different types of hearing loss to aid their communication needs and thus enhance the quality of their lives.

In their study of technological change and economic theory Freeman and Perez (1988: 85) write that technological change involves “technological revolutions which bear with them ‘quantum leaps’ in industrial productivity…and..each revolution is composed of a ‘cluster of radical innovations’.” They also say that once innovations are transferred to the manufacturing stage, accepted and reach national economies “they become ‘locked-in’ to a universal developmental trajectory.” This observation is very apparent in many industries, for example the reluctance of the motor car industry to rapidly develop alternatives to the petrol engine. It is also true for the hearing aid and newly developing cochlear implant manufacture, where different technological innovations produced different paths to help hard of hearing people to hear. It would seem that these two industries developed independently of each other, and future attempts to improve hearing could in all probability follow a different path.
Hearing Aid Technology

For three years in the early 1950s hearing aids were the only market for the transistors that were initially developed and trialled for telephone use. This changed very bulky hearing aids into small devices that could fit behind the ear (Hearing with Transistors: 1997). Today, hearing aids are developed and manufactured by corporations where profit has to be an inescapable objective. Freeman and Perez (1988) use the term ‘technoeconomic paradigms’ to describe the complete rethink in the manufacturing process to accommodate a new technology. They say that an essential element is necessary in a paradigm change, and for the late 20th century the microchip was the ‘key factor’ (1988: 54-60). Whilst their theory is at the macro-economic level, I argue that the same is also true at the micro-level of hearing aids, cochlear implants and computer technology.

For the majority of hard of hearing people the hearing aid was a device they were reluctant to purchase and wear. One concerned North American hearing aid manufacturer, aware that hearing aid sales did not meet projected targets and advertising expense far exceeded sales income, conducted market surveys to determine possible reasons for this. The most important of the five principal reasons were “Hearing instruments have a stigma attached to them, and, Hearing instruments cost too much, especially in relation to their value” (Kochkin 1993:1). Several conclusions from a further survey in 1998 could be interpreted in favour of the company’s profits rather than the hearing aid user. Among these was:

Public relations and advertising should probably be targeted to the “victims” of hearing loss, namely family members who attempt to accommodate the individual’s hearing loss. Perhaps a 10-15 minute audio or video geared toward helping spouses or children of hearing-impaired individuals to effectively confront family members in a state
of denial could have a positive impact on market growth. (Kochkin: 1998:37).

It is not only the large companies that are manufacturing hearing aids, or their components. Smaller enterprises are competing for market share. Furthermore, evidence suggests that profit above expenses is the primary motive for production. One such company research chief that supplies ‘programmable chips for hearing aids’ says “We’re already revenue-positive in a technology with a lot of potential” (Byfield 2001:35).

From the above examples I argue that commercial interests identify hard of hearing people and other purchasers of hearing aids, such as government agencies, and other bodies that assist with funding, as consumers. Given the relationship between age and hearing loss there is an increased market potential for hearing aids as the population ages. However this new market opportunity should perhaps be put aside by the manufacturers until the important issues such as why people would prefer to avoid hearing aid use, are overcome.

**Stigma of Hearing Aid Use**

As stigma appears to be one of the main reasons given for the lack of hearing aid purchase, it is an appropriate time to briefly explore this concept. Goffman (1963:4) defines stigma as “a special kind of relationship between attribute and stereotype” and further “an attribute that is deeply discrediting.” However, he qualifies this by saying that it is only those attributes “which are incongruous with our stereotype of what a given type of individual should be” (Goffman 1963:3). Furthermore, Goffman clearly regards lack of hearing to carry a stigma, for he uses examples and quotes related to deaf and hard of hearing people at least seventeen times, referring to them
Consequently I conclude that he considers stigma to be attached to all those with a hearing loss no matter when it was acquired. Many of Goffman’s examples of stigmatised people include those who possess radical and very rare attributes such as a person with no nose, or very ambiguous characteristics such as a weak will, and shameless scoundrels (1963:4). Furthermore he situates deaf and hard of hearing people in the same generalisation when he says “…stigmatised persons have enough of their situations in life in common to warrant classifying all these persons together for the purpose of analysis” (Goffman 1963:146). He further refers to those people without a specified stigma as ‘normal’. Even though deaf and hard of hearing people may be stigmatised outside their social group, from my observations, when in their social groups they tend to esteem themselves and their friends and acquaintances. One example Goffman provides to support this is of a hard of hearing person who attended a school where people took hard of hearing for granted, “What a luxury to say out loud to someone, ‘ye gods, my battery’s dead” (Goffman 1963: 20). These people that share a common stigma are referred to by Goffman as ‘own’. On the other hand, Higgins (1980: 27) did find that hard of hearing people are not usually members of a group of similar people who could reinforce positive feelings. Goffman further points out that stigmatised people have the same beliefs about stigma as ‘normals’. Consequently when in their presence a stigmatised person may feel “self hate” and “self derogation” (Goffman 1963: 7).

The notion of stereotype is closely related to stigma, and is defined as “a set of inaccurate, simplistic generalizations about a group of individuals which enables others to categorize members of this group and treat them routinely according to those expectations” (Jary & Jary 1991:629). People who are so labelled as a separate group are “expected to display behaviours and traits stereotypically linked to those categories” (Pfuhl & Henry 1993:160). However, Taylor (1999) notes that whilst the
stereotype of deaf people is of being slow and dim-witted, the researching of Deaf communities has found that this was not the case. Furthermore, it was also found that whilst members of the Deaf community are fully aware of the stereotype, it does not appear to affect them. However, this does seem to be conditional, “although they could act the deaf role in public, sometimes mockingly or for strategic reasons” (Taylor 1999: 267). Notwithstanding, hard of hearing people that do not have the social support, or a separate sub-culture, as do many people who are deaf, may respond as suspected from the stereotype. These people, most of whom are adults, will be well aware of the stereotype associated with deafness. They have even perhaps laughed in the past at comic jokes usually directed at elderly folk in TV situation comedies. ‘You don’t have to shout, I’m not deaf’, or ‘If you heard that you can’t be deaf’ are well-known and obvious examples. Furthermore, there seems to have been little change in the perpetuation of this stereotype in popular novels and movies. I argue that for older hard of hearing people this stereotype is strongly linked to hearing loss of any kind and could possibly be one of the main contributors to the perceived stigma associated with hearing aids. Notwithstanding, when I questioned my Ear, Nose and Throat specialist about people’s reluctance to use hearing aids, his response was “they will purchase and wear a hearing aid when their hearing loss becomes so bad that they cannot hear any sound” (Miller 2002).

**Cochlear Implant**

As described by Ramsden and Graham (1995:1588),

> The cochlear implant is an electronic device that is inserted into the inner ear of a totally deaf person to introduce or restore the perception of sound. An external detachable component comprises a microphone, a small battery powered device for processing the signal, and an induction coil that transmits the refined signal through the skin to the implant.
The costs associated with the development of this technology were, and still are, enormous. In Australia, where the world’s first multi-electrode implant was developed, the funds came from grants and donations from appeals. However, once the success of the technology became apparent, it took a further 7 years from the time of the first operation in 1978 to gain approval from government health bodies in the USA for mass production (Clark 2000). By the start of the 21st century, independent Cochlear Corporations are listed on the stock exchanges of several major countries, and together with two other companies supply the United States market. These public companies must satisfy shareholder expectations with acceptable dividends, consequently the cost of a cochlear implant device (CI), is expensive. In Australia a CI costs is approximately $Au20,000.00 exclusive of surgical fees, whilst in Britain and USA the comparative costs are far higher. An English participant in this study claimed that her CI cost her 60 thousand pounds sterling. There is a lengthy waiting list for a government-subsidised implant for eligible people in Australia, and this is the only option available if a person has no private health insurance or other available funds to cover the cost. I see government subsidy as only a partial acknowledgment of deaf and hard of hearing people. From my experience, a hard of hearing person who has lost all aidable hearing, should be eligible for an immediate cochlear implant. In their article researching cost of CI implantation in Britain, Ramsden and Graham (1995) concluded that as “More than 90% of adults with the implants reported an overall improvement in their quality of life and reduced dependence on others. In a cost utility analysis, cochlear implantation compared well with other treatments currently available in Britain.” They also pointed out that “each device plus surgery and rehabilitation costs between 25000 (pounds sterling) and 30000(pounds sterling).”

What may seem like a miracle for many hard of hearing people, can also be viewed by some with antipathy. As with other surgical procedures there is a risk of failure. There is also the possibility that the CI will not work. The implants do not suit all people with a
profound hearing loss. Neither do they all want one. For many deaf people, comfortable in their social networks, a CI is not necessary, nor would the sound be beneficial. Currently in Canada, Great Britain and the US, programs designed to implant young deaf children are causing dissent in the deaf community where the demise of their culture is foreshadowed. In the wider community the debate focuses on the ethical issues of the rights of the child (Swanson 1997; O'Donoghue 1999). On the other hand, many hearing parents who have a deaf child are in favour of the surgery. It has been found that the earlier a child is exposed to sounds the more successful will be their acquisition of a verbal language (O'Donoghue 1999).

It has been said that hearing aid and cochlear implant technologies are similar, therefore cochlear implants can be considered hearing aids. I argue that this would be equivalent to classifying the surgical repair or replacement of the lens of an eye with that of spectacles. However, perhaps because of the general lack of knowledge of human hearing anatomy and its connection with physics, it is difficult to comprehend the dissimilarities between a hearing aid and a cochlear implant.

Computers

For an increasing number of people with a severe or profound hearing loss, the Internet is perhaps the single most important technology available at the start of the 21st century. As mentioned above, many of these people cannot or do not wish to wear a hearing aid, or are unsuitable subjects for a CI. A personal computer gives them the ability to communicate with others in a meaningful way, and may improve their quality of life. After researching this area I could find no relevant information to support or counter this claim. However, studies of isolated elderly people have shown that the Internet can provide a social benefit for these people (Noer 1995; Wright 1999). It should be noted that in these studies no mention was made of how this technology may benefit hard of hearing people of any age. I am not disputing that isolated elderly
people do need social contact, but if they can still hear, their need for contact may not be as great as any hard of hearing person who gets minimal benefit from other forms of social interaction, even when they wear a hearing aid.

The hardware, software and telephone technologies necessary for individual Internet communications, come at a monetary cost. However, the purchase price of personal computers and the Internet access costs have decreased in recent years, as a direct result of the increased demand by consumers generally, not just by hard of hearing people. They are now widely available in the developed world and are confidently used by the younger generation who learnt to use computers as part of their general education. Older persons who have acquired computer skills from their work experience before becoming hard of hearing will use these skills easily. However those people who are not computer literate may find it difficult to use the computer and the Internet unless a friend or family member can convince them of the benefits. Computer education classes for seniors are becoming available, but these people probably still need a reliable support network to guide them through the multitude of unexpected problems that do arise with this form of technology. Of course, once a person becomes confident with computer use, engaging the wider network of Internet users can solve problems.

Unlike hearing aids and cochlear implants, personal computers do not carry any stigma and are widely used throughout the developed world. Furthermore, there is no surgical risk associated with them as there is with cochlear implants, and generally they are very reliable and comparatively cheap. Paradoxically, the personal computer is the one technology that was not designed specifically for hard of hearing people, but is becoming the medium through which these people are forming communities that were denied them in the past.
Where there are towns with public facilities, it is becoming increasingly common to find links to the Internet, and hence email access, for example in public libraries. For those people who are unfamiliar with Internet use, the staff are ready to assist. This public access to technology has connections with Bush’s (1983) propositions for technology.

**An Alternative View of Technology**

There is another way of looking at technology. The common and generally thought of definition links it to a ‘quick or tech fix’, as I have briefly described above. Feminist Corlann Gee Bush (1983: 164) sees technology as an equity issue, and says,

> Technology is a form of human cultural activity that applies the principles of science and mechanics to the solution of problems. It includes the resources, tools, processes, personnel, and systems developed to perform tasks and create immediate particular, and personal and/or competitive advantages in a given ecological, economic and social context.

These criteria are listed under ‘development’, ‘user’, ‘environmental’ and ‘cultural’ contexts and are then further analysed. I find it hard to reconcile aspects of Bush’s contexts with the development of the Cochlear Implant and can see only user benefits from its production. For example in Bush’s ‘user context’ the criteria to be explored include tools and techniques displaced, interplay with other current technologies, personal and competitive advantage, and second and third level consequences for individuals. The outcomes from examination of these criteria could suggest a possible disadvantage for some individuals. As the cochlear implant is definitely the technology of last resort for profoundly hard of hearing people, no technology is displaced nor are their other current similar technologies that are affected. This new technology has created employment and competition between companies that have materialised since its inception. Following Bush, cochlear implant technology utilises scientific principles
for both its effective manufacture and use. Electronic circuitry converts sound energy into electrical energy to be interpreted at a molecular level in the brain into what appears to the recipient as meaningful sound.

The technology of hearing aids and cochlear implants utilise a multitude of materials, tools, systems and processes from inception through to the end product. However, it is not the purpose of this analysis to document each stage of development. It is sufficient to say that when using Bush’s environmental context to investigate this technology, there will be some form of contribution to global environmental pollution.

Bush’s equity analysis further lists a cultural context, with the following criteria to be addressed: the impact on sex roles, the social system affected, the organisation of communities, and the economic system involved and the distribution of goods within the system (Bush 1983: 164). As mentioned earlier in the chapter there is the very real probability that the Deaf culture and consequent deaf sign language will gradually disappear because of cochlear implanting of babies of hearing parents. As these children mature they will probably belong to the mainstream hearing culture and not the deaf culture. Presently there is much dissension within deaf communities because these people can see a future where their numbers have so diminished to bring into question the sustainability of their visibly recognisable language. Anecdotal evidence suggests that where a deaf child is born to deaf parents, these parents are objecting to the chance for their child to be implanted.

When Bush’s thesis is applied to computer technology I argue that analysis does prove significant, and not just for cochlear implanted people but also for the majority of people with a hearing loss. The hard of hearing people who have gradually become socially isolated have found a means to overcome their disability by communicating online.
It is Bush’s ‘user context’ that offers the most significant analysis for people with hearing loss. Once again, there are ‘obvious tools, techniques and systems displaced by’ computer technology and these need not be explored here. However, since the 1980s computer technology has moved from the realm of commerce and into the homes of a significant percentage of the population. Bush’s ‘second and third level consequences for individuals’ provides a glimpse into how this technology is affecting the lives of many hard of hearing people. For these people, with the loss of hearing no matter how slight, there can be a gradual withdrawal from conversation contributions. It is at this point that it cannot be emphasised too strongly that the ability to hear verbal communication is essential for everyone, and because of its universality it is often taken for granted. There are many groups comprised of disabled people on the Internet, and apart from people who have speech impairments, the members of these groups will be able to hear well enough off line to communicate with others either face to face or by phone. Now hard of hearing people who have discovered Internet communication can once again enjoy conversations also.

Whatever view of technology is used, the latter part of the 20th century has been a watershed for hard of hearing people. Historically, hard of hearing people have not had a voice, but technological devices coupled with major social movements has enabled these people to gradually emerge from obscurity.
Chapter 3:

Theoretical Perspectives: Understanding Disability.

Having briefly woven the history of hearing loss into the historical references of disability, it is now appropriate to discuss aspects of disability per se and how this relates to hard of hearing people. In this chapter I will focus upon four areas relating to disability. First, it is necessary to show how disability is defined. Second, I shall outline how disability is recognised by the state. I will then review the social and medical models of disability as theorized by academics. Finally I suggest that a point of intersection of these two models, that incorporates commercial aspects, is appropriate when considering the hearing loss experienced by people in the hearing community and how they may establish social networks.

Common Understanding of Disability

Dictionary definitions of disability ignore the diminished sensory capability and focus on the reduced physical or mental capacity to perform tasks or functions. Although the wording varies slightly, the intent of dictionary definitions are essentially the same. The Macquarie Dictionary (1981: 520) defines disability as the “lack of competent power, strength, or physical or mental ability; incapacity.” Longman (1986: 244), defines disability as “the condition of being disabled; *specific* inability to do something (eg pursue an occupation) because of physical or mental impairment.” The Australian Concise Oxford Dictionary (2004: 394) says disability is “physical incapacity, either congenital or caused by injury.” From these definitions, and hence to the world at large, it would seem that the condition of disability refers to physical and/or mental conditions, which may limit a person in some way.
Not only are disabled people a marginalised group in mainstream society, but until recent years disability has not been considered for academic investigation. Bearing in mind that people with disabilities form a proportion of most social groups, it is surprising that no definition is provided in the Jary and Jary (1991) Dictionary of Sociology. This omission is an example of the lack of recognition given to disability generally in sociology. Just as Women’s Studies became an area of research as a result of feminist activism, so too did disabled people and their supporters bring disability out from the apparently personal realm to give it a public voice.

However, the public face of disability is more often than not associated with something readily observable, for example wheelchair dependency. There can be no doubt that it is because of the lobbying activities of people confined to wheelchairs that most public buildings now tend to have wheelchair access, washrooms that accommodate wheelchairs, and many public carparks usually have the ACROD blue parking space for people with such disabilities. These visible accommodations are now commonplace. In her book *Feminism Confronts Technology*, Judy Wajcman (1991:163) uses wheelchair ramps to make the point that technology sometimes has unintended uses when she shows that women can use them for prams. These examples suggest that frequently disability is equated with an observable physical disability, and as a result it becomes apparent that there are relatively inexpensive and visible ways for organisations to demonstrate that they are catering for disabled people.

**Disability – A Political Framework**

The recognition of disability by the State started its slow movement from the private to the political just after the second world war. The newly formed United Nations gave birth to the disability movement when it adopted the Universal Declaration of Human Rights in 1948. The declaration claimed “that all human beings are born free and equal in dignity and that everyone is entitled to all the rights and freedoms set out in the
Declaration, without distinction of any kind” (UN Convention [online] n.d.2003). The altruism of this declaration is laudable, however considering the huge amount of post war reconstruction needed in many European and Asian countries it is not surprising that it took a further 27 years before the Declaration on the Rights of Disabled Persons was adopted in 1975.

Just as the terms deaf, hearing impaired, hard of hearing, late deafened, acquired deafness, and acquired hearing loss are often used interchangeably, so too are the descriptions ‘impairment’, ‘disability’, and ‘handicap’. However, it was in 1980 that the World Health Organisation (WHO), a branch of the United Nations, differentiated between the three in terms of health. They defined:

**Impairment**: as any loss or abnormality of psychological, physiological, or anatomical structure or function.

**Disability**: as any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

**Handicap**: as a disadvantage for a given individual, resulting from an impairment or disability that, limits or prevents the fulfilment of a role that is normal, depending on age, sex, social and cultural factors, for that individual. (UN 1980: [online] 2003).

The document that included these definitions was called the International Classification of Impairments, Disabilities and Handicaps (ICIDH). From the lengthy descriptions of impairment, disability and handicaps in the document it has been observed that “just one kind of impairment can cause multiple disabilities and imply several handicaps” (Functionality, Disability and Health [online] 2003).

These three terms are generally understood to have the same meaning. For example, I have an acquired hearing loss that could well be described as a sensory impairment,
as a disability, or as a handicap, with no other meaning attached to the condition other
than perhaps deafness or being partly deafened. Indeed I have used the words
disability and impairment in conversations over the years with no apparent confusion
for the person with whom I was conversing. Harris (2001:2) similarly says

I believe it is important to understand what might be harmful about
conditions variously described as disabilities, handicaps or impairments.
I do not believe there are any generally agreed sharp distinctions
between these three concepts as discussed by Jones, nor are they
sharply distinguished in colloquial English.

We know that there are differences between deaf people who use sign language to
communicate and those that use hearing aids and communicate orally, but it is
debateable as to which classification defines each. As Corker and French (1999:5)
quoting Corker (1998) say “this difference cannot always be concretely described in
terms of disability or impairment. It is interesting to observe how the term ‘disabled’ is
applied (or not) in these two cases.”

These classifications of impairment, disability and handicap are a contested site in
academia. The term ‘handicap’ in the UK “has been rejected by many commentators in
favour of impairment because of the patronising connotations of being ‘cap-in-hand’,
that is, begging” (Marks 1999: 139). Set against this explanation is how the term
‘handicap’ is used as a levy on advanced players so as to even out the game, in horse
racing and a variety of competitive sports. If used in this way to distinguish people with
a disability from the general population then the implication is that it is the latter group
that is handicapped. On the other hand Jones (2001) points out that in the revised
WHO classification of 2001, ‘handicap’ has disappeared. He suggests that there has
not been sufficient distinction between environmental factors that can add to disability,
and societal attitudes that can cause an added burden for people with disabilities. He
therefore defines handicap as “the impairment rampant in the rest of us, the inability to overcome our own prejudices, which ensures that any disadvantage resulting from impairment or disability is magnified” (Jones 2001: 5). This definition could apply equally to people who do not have a disability. For example, in the way that women who attempted entry into the male dominated print industry were treated. In a study of this industry it was found that women met with a well organised and prolonged campaign by the male workers. Such arguments as the following were used: the lack of physical strength, the lead used in the printing process caused infertility, “a tendency to destroy the powers of maternity”, women’s lack of mental ability, and their emotionality (Cockburn 1983: 204). Following Jones’s (2001) definition, by attempting to justify their own existence these male print workers were exhibiting the prejudices that handicapped them from rational judgement. Notwithstanding, in my view none of these understandings of the term justifies its use in connection with people with an impairment. Consequently I consider the use of the word ‘handicap’ as anachronistic.

The bureaucracies that formulated the WHO’s original definitions of impairment, disability and handicap further revised and changed these to formally include disabilities under the supervision of health professionals. Consequently a new classification system was proposed which for a time was titled International Classification of Impairments, Disabilities and Handicaps (ICIDH-2). However, when the World Health Assembly endorsed this new classification in May 2001 it was given the title International Classification of Functioning, Disability and Health and “for historical reasons, hereinafter referred to as ICIDH-2” (World Health Organisation, 9 April 2001). This new protocol appears to have been devised as a tool to universally classify people according to bodily functions, bodily structures, participation and activity, and environmental factors, abandoning the three previous classifications as defined in 1980. This relatively recent classification system appears to be extremely complicated and may not stand the test of time, nor meet the daily personal needs of
those people that it is intended to help. It is probable that differences of meaning and omission will occur when the ICIDH-2 is translated into the different languages of the member nations. As we can see, this was an elaborate attempt to include all the peoples of the world who are seen by some to have some level of impairment that restricts their enjoyment of life. It can also be seen as the formalizing of an extension of control that the member countries were establishing over people who did not conform to the recognised view of ‘normal’. Moreover, it is entirely possible that many third world and other countries that do not enjoy the rule of law, even though they may be members of the UN, have not enacted appropriate legislation to recognise and support their disabled and marginalised citizens.

Some third world countries are taking steps to assist their disabled citizens. At the 2004 International Federation of Hard of Hearing (IFHOH) conference, a resolution was passed to explore ways in which hard of hearing people in some Indian communities may be assisted with basic hearing aids. Indonesia, with Japanese Aid is working to train specialists in treating hearing related problems (IFHOH: 2004). However Indonesia, along with many of the poorer nations have very humid climates, and hearing aids and cochlear implants are very susceptible to humidity and moisture of any kind. Consequently the hearing aids and speech processors used in cochlear implants will either not function effectively in those environments, or different climate compatible devices will have to be developed.

In Australia specific groups were formed to help hard of hearing people such as Better Hearing Australia and Self-Help for the Hard of Hearing (SHHH). Many of these organisations were in existence well before equal opportunity legislation, and these are the groups that have lobbied for improved conditions for their members, or for those disabled people that the members represent. It is as a result of this lobbying that the Australian Parliament legislated to recognise people with disabilities when the Disability
Discrimination Act became law in 1992, some 47 years after the Declaration of Human Rights was declared by the United Nations and 12 years after the WHO defined the differences between impairment and disability (Disability Discrimination Act 1992 [online]). However, the passing of Disability Legislation did not provide the outcomes expected by disabled people. Available aid and facilities are still dependant on the effective lobbying of government and private industry, and the testing of legislation, for example Disabled People’s International v Telstra Corporation Limited 1995 (available [online]). Presently, for example, in Australia there are efforts to incorporate movie captions in all cinemas (Media Access Australia [online]).

**Theorising Disability**

The initial concepts concerning disability were developed by academics with disabilities. For example Shakespeare, an academic who has contributed to the discourse, has achondroplasia (Jones 2001: 2). Michael Oliver another academic and early disability theorist, acknowledges that he became disabled as a result of a spinal injury (Oliver 1996:8). It has also been argued that it is not essential to be disabled to theorize disability. Davies (1995), the hearing son of deaf parents, has argued that a person does not have to be disabled to theorise disability. However, this view is not shared by Oliver, who says “if disabled people left it to others to write about disability, we would inevitably end up with inaccurate and distorted accounts of our experiences and inappropriate service provision and professional practices based upon these inaccuracies and distortions” (1996:9). I would add to this that a person without the use of legs, as Oliver is, may likewise give a distorted account of a hard of hearing person, just as a hard of hearing person may not give a true account of the experiences of a deaf person. Indeed, Seymour (1998: xii) who has a progressive arthritic condition acknowledges “while the disability may have legitimated my right to conduct the research in the eyes of the informants, it may also have influenced the information I sought and the importance I attached to aspects of the material.” As
disability theory is still evolving, and like other theories it is not absolute, there are and will always be different points of view.

The consciousness raising of people with disabilities initiated disability theory in a similar fashion to feminist theorizing being predominantly by women. However, history has shown that there are exceptional people with the maturity and depth of understanding who have written literature that conveys justifiable meaning for groups to which they do not belong. One such example is that of Marks (1999: xii) whose initial interest in disability was triggered when working in the field of mental illness. Marks says that she had to address dilemmas in her study which were “engendered by my position as a member of a privileged group of able bodied people."

Before proceeding with a discussion about models of disability it is important to stress that members of the Deaf community do not refer to themselves as disabled. They communicate primarily using sign language and as such regard themselves as belonging to a cultural minority. As Davies (1995:xiv) says “the Deaf do not wish to be associated with, say, autism or schizophrenia. They see their state of being as defined not medically but rather socially and politically.” It is with this in mind that I briefly review the two models of disability that are recognised at the start of the 21st century.

Disability Models

Theorists have examined various models or discourses that propose new ways of observing disability. Social model theorists rely on the first WHO definitions of disability and impairment, where disability is a social construction and impairment “refers to as a physical attribute of the body” (Corker & French 1999:2). Wendell (1997:260) proposed a feminist theory of disability, and some recent additions to the study of disability are described as postmodern (Corker & Shakespeare 2002). Medical
sociologists argue that medical professionals tend to equate disability with illness, and for example view deafness as an illness or disease. Fulcher (1989:42) argues that in Australia, as well as the medical model there is the ‘rights’ view, which is seen as a response to overseas civil rights movements. She also refers to a ‘charity model’ which “suggests that people with disabilities need help from people not seen as disabled”. The common thread joining each of these discourses is that no single impairment is studied, although several are referred to as examples.

As previously stated, hearing loss acquired after learning to speak is ignored by all theorists who favour ‘deafness’ as an example of disability in their work, implying perhaps that later hearing loss is not considered a disability by disability theorists. In the light of this I argue that given the comparatively recent inclusion of disability as a separate discourse in academic studies, post lingual hearing loss can and should be recognised as a legitimate example of a disability.

Every participant in this study has availed themself of the assistance of medical and other technologies to participate as fully as possible in the hearing world. The use of appropriate surgical procedures or the purchase of assistive listening devices evidences the reliance on technologies by hard of hearing people. In a number of cases, both have been employed. Unlike some deaf people who are reluctant to find a remedy for their hearing loss, hard of hearing people in the main do seek and value the help they receive. It is with the monetary cost of this in mind, and referring back to Freeman and Perez (1988) in chapter two, who introduced the term “techno-economic”, I suggest a commercial discourse of disability, aligned to both the medical and social models of disability, could be theorised.
Medical Model of Disability

The term ‘medical model’ is not a term that is used by the medical profession to describe what they regard as the scientific understanding of the body. As Marks (1999:52) points out “it is a term that tends only to be employed by those critical of medical practices.” However it is used by sociologists and disability theorists to describe a major approach taken by social policy makers to deal with disability issues. For those that subscribe to this medical model approach, the core belief is that the disabled body is flawed and must be restored to normality. It is considered that the primary concern of the medical professionals is to treat the disability as a separate entity from the person and how that person relates to their environment. The focus in the medical model is on treating the disability rather than the person with the disabilty. Indeed, as a result of a 21 year study of medical students who entered medical school in 1967, Margaret Shapiro found that as those people matured as medical professionals “there was a general shift towards a less patient-centred perspective after respondents had been in contact with clinical role models and clinical work” (1989:221).

In his outline of the influence of Western philosophy and science on the development of medical thought, Capra (1982:122) points to the influence of Descartes and says “his strict division between mind and body led physicians to concentrate on the body machine and to neglect the physiological, social and environmental aspects of illness.” Fulcher (1989:41) quotes Brisenden (1986:174) who maintains that “the social world is …steeped in the medical model of disability.” Indeed, prior to disabled scholars entering the field, disability tended to be treated as a problem studied as a health issue by health care and social workers without reference to, or consideration of, the broader social issues affecting the people at its core (Marks 1999:4).
There are many examples of how disability researchers view the medical model of disability. It is a contested site where not all give the same name to this model. Nor is there consensus as to where this approach is primarily implemented. For example, British theorist Oliver (1996: 31) says “for me, there is no such thing as the medical model of disability, there is instead, an individual model of disability of which medicalisation is one significant component.” Countering this, another British theorist argues that in the United Kingdom “right up to the present day, a ‘personal tragedy’ or medical model has prevailed” (Drake 1999: 197).

It is not only disability theorists who are critical of the limitations of the medical model. Many medical sociologists with differing perspectives likewise are critical of this model. Petersen has argued that there “is growing disenchantment with medical knowledge and its limitations as a source of knowledge on health and illness” (1994:39). One notable site at the present time is the debate in Australia as to whether new born babies should be tested for deafness. The Universal Newborn Hearing Screening still has pockets of resistance as to its effectiveness, but is now expected “in the United States and Canada, the United Kingdom and many European countries” (Wake 2002: 1). The result of a positive test may be the use of hearing aids or the possible medical intervention with a cochlear implant. As O'Donoghue (1999) finds from British research, “The vast majority of candidates for implants, however, are congenitally deaf; over 90% of them have normal hearing parents who want their child to hear and speak. Parents who think that deafness is a way of life and not a disability are unlikely to consider implantation.” Perhaps “a recognition of the need to develop new ways of understanding health, illness and healing” suggested by Petersen (1994:39) in this example, would be to counsel the deaf parents to accept a medical intervention that would give their child the benefit of a second language as well as the signing that it will learn from being in the presence of its parents.
Whenever the criticisms of the medical model by disability theorists, they do not mesh well with my view that people who become disabled will try to regain a level of independence by whatever means is available. Affected people may acknowledge that a complete return to their former self is impossible, however where medical intervention has a possibility of some success many people may take the chance to remain a participating member of their extended social network. Moreover, Drake (1999:205) says, “there are other disabled people, perhaps some of those who acquired impairments later in life having earlier been ‘non-disabled’, who may welcome medical intervention as a way of ridding themselves of what they regard as troublesome and unwelcome impairments.” A well-publicised example of the willingness to use medical intervention is the effort and expense that the actor Christopher Reeve employed to regain the use of his limbs after being injured in a fall from a horse. Not only was Reeve attempting to help himself, he was also aiding medical research, which eventually has the possibility of helping others with a similar injury. If and when this type of medical research is successful it has an enormous commercial potential. Notwithstanding, Seymour (1998: 53), whose work focusses on people with physically damaged bodies found that although social interaction has been disrupted they developed ongoing processes of re-embodiment to reshape social interaction. However, I argue that no matter how damaged a person’s body, good hearing is required for social interaction. While many hard of hearing people have used surgery as a way to improve their hearing they may never be completely ‘rid’ of hearing loss. Furthermore Seymour says that physically disabled peoples’ social interactions can be reshaped by using new ways to use their bodies “in the on-going process of re-embodiment” (1998: 53). No doubt many of these people will have had some surgical procedures to allow greater comfort, but no matter how damaged is a person’s body, social interaction normally involves speech and hearing.
Social Model of Disability

Disability theorists conceived the social model of disability as an alternative view to the medical model of disability. They argued that the medical model was inappropriate because many disabilities are not related to illness and do not require medical intervention. Whereas the medical model concentrates on individual impairments, the social model does not differentiate between these, focussing instead on “the ways in which the environment is designed with a minority of young, fit and non-disabled people in mind” (Marks 1999: 4). The scholars favouring this social discourse take the view that disabled people must actively fight for their rights and be treated equally with other members of the larger community (Marks 1999: 5). Earlier in this chapter I gave some visible examples of wheel chair access and ACROD parking spaces that are clearly the result of the political activities of some disabled people. The captioning of prime time television programmes in Australia is another less publicised outcome of lobbying by the combined group of hard of hearing and deaf people. Independently, each group may not have succeeded, however their aggregation gave them political strength. Perhaps if Petersen’s (1994:39) “new ways of understanding” is viewed from a social model perspective there could be a greater emphasis on teaching hearing people to sign. Anecdotal evidence suggests that in some Western Australian schools that include deaf students in their population, hearing students are learning to sign so that they can communicate with their deaf schoolmates. One interesting example of the success of signing as a second language for hearing people comes from the Martha’s Vinyard community in the USA. Historically the island was settled by a group of people that had a high incidence of hereditary deafness. These deaf people learned to sign as a natural part of their communication and from attending a school that taught by sign. For 250 years, with inbreeding, the community of both deaf and hearing people signed to each other. Signing was so much a part of this community that even after 20th century educational practices outlawed sign in favour of spoken language,
and the deaf members of that community died out, signing was still used by many of its elderly hearing residents (Sacks 1991:34).

I would argue that the medical and social discourses with reference to disability are not mutually exclusive, but intersect. This point of union, or overlap in contemporary societies is an appropriate site for the conceptual study of hearing loss acquired after learning to speak.

**Commercial Aspects of Hearing Loss**

For a hard of hearing person to enjoy a reasonable level of social communication and physical security, a reliance on various technological devices is essential. Furthermore, they were not all designed to fit the purpose by medical professionals or social activists. These devices, and importantly, their maintenance, may be costly for the user. It is my view that the financial circumstances of the hard of hearing person, combined with modern technology, will determine whether they are labelled ‘disabled’ by the state. In Australia, children under 21 years, qualified people over 65 years and unemployed people are eligible for financial assistance. For those people who do not meet these criteria, regardless of their economic circumstances, there is no government assistance. Unemployed hard of hearing people who must be classified as ‘disabled’ to receive assistance may feel further socially isolated because of the compounding effect of the stigma associated with hearing loss. For the remainder of hard of hearing people who fall outside these criteria, they become consumers of hearing assistance devices, or if they cannot manage the costs involved, become more socially isolated if their condition worsens. In either case, technology and its monetary cost are the common denominators. However, for those people who use technology, there is another cost involved. This cost is one of dependence on the technologists that monitor and maintain these devices.
I have shown in this chapter that disability is a contested site with many players and the normal everyday understanding of the term being only a small part of the wider political network that has evolved since the late 1940s. As Human Rights agendas grew, academic theorists have offered models to define and refine disability issues, occasionally giving examples of specific disabling conditions. Although deafness is one of these examples given, no mention is made of hearing loss that developed after speech was learned, suggesting that this condition is not a disability. However to enable hard of hearing people to participate in social exchanges, even in a limited way, they must be able to afford available technological aids. Whilst the state may provide some financial assistance, many hard of hearing people are excluded. In the following chapter I will explore the concepts of community and how hard of hearing people have taken advantage of a relatively affordable technology to join with others in a non threatening environment.
Chapter 4:

Theoretical Perspectives: Conceptualizing Community.

Putting the case for the documentation and preservation of Australian sign language (Auslan) Johnston (2004) concedes that “the size of the signing Deaf community in Australia is considerably smaller than some previous estimates of the size of the Deaf community”…..and….“the signing Deaf community is about to experience more dramatic changes and an eventual decline” (2004:15). It is perhaps ironic that at a time when early detection, improved hearing aid technology and cochlear implantation is reducing the number of potential members of the Deaf community, other forms of technology are making it possible for people who are hard of hearing, or deaf, to form different community relationships. In this chapter I outline the 19th and 20th century sociologists’ conceptualisations of community in order to aid our understanding of communities in the age of the Internet. This is followed by a discussion of recent conceptualisations of virtual community. Finally, in the light of this discussion of community I shall describe the key features of a community of people who are hard of hearing and who communicate with each other by e-mail. This I shall refer to as a Hard of Hearing Online Real Community which has similarities to the virtual communities described by several recent sociology theorists. However, and most importantly, because its members share a disability significantly affecting social communication, I argue that it is qualitatively different from other virtual communities.

Definitions of Community

Simply put, a community may be considered to be a group of people living in a particular “locality or place – also sharing religious beliefs, tasks, professions or interests” (The Australian Concise Oxford Dictionary 2004:279). The Macquarie Dictionary defines community as “a social group of any size whose members reside in
a specific locality, share government, and have a cultural and historical heritage” (1981:385). On the other hand it has been considered by many theorists to be almost indefinable. Poplin says “one need not go far into the literature of sociology before encountering the term community. For alert readers this can become a source of utmost confusion” (1979:3). In fact it is recorded that “in the mid-1950s an enterprising American sociologist had uncovered more than 90 discrete definitions of the term in use within the social sciences” (Cohen 1985:7). Furthermore, as recorded by Jary and Jary (1991) after Worsley’s (1987) suggestion, there are three broad meanings for community:

- “The community of locality;” that he describes as “human settlement within a fixed and bounded local territory.”
- “A network of interrelationships” (Stacey 1969). Worsely (1987) says “in this usage community relationships can be characterized by conflict as well as by mutuality and reciprocity.”
- “Particular type of social relationship” such as ‘community feeling’ and ‘community spirit’ (1991:99).

The above definitions and meanings given for community would refer to the actual physical and emotional relationships between people. However, they can also be incorporated into our understanding of social relationships that are divorced from the physical and transferred into the virtual.

**Historical Community Theory**

The exploration of community and how it relates to the online community that I shall describe starts with Tonnies’ theory of Gemeinschaft and Gesellschaft. A search for the precise English translation of these German words proved problematic. Gemeinschaft may mean an association, collective, communion, community, fellowship, and company. Similarly Gesellschaft, may mean a company in its various
commercial forms, society, party, companion and various other social and commercial meanings (Werner 2001 [online]). On the other hand Abercombie et al (2000: 149) say Gemeinschaft is “usually translated as ‘community’” and “this term is usually contrasted with Gessellschaft or ‘association’.”

Tonnies was writing at a time in the late 19th and early 20th centuries when the social systems of city life were emerging with an increasing significance from a previously rural dominated environment. It was also the time when social theorists were attempting to use scientific method to establish laws for their theories. For his theory of Gemeinschaft Tonnies established three main laws that state:

- Relatives and married couples love each other or easily adjust themselves to each other and think along similar lines. Likewise do neighbours and friends.
- Between people who love each other there is understanding.
- Those who love and understand each other remain and dwell together and organize their common life (Loomis 1957:197).

Using these laws to describe his theory, Tonnies said Gemeinschaft represented the social relations of the village community where family relations, locality and cooperation between individuals were important. On the other hand, Gesellschaft represented the social order necessary to enable a larger city to function. Tonnies does not provide laws for his theory of Gesellschaft but states that the theory of Gesellschaft deals with the artificial construction of an aggregate of human beings which superficially resembles the Gemeinschaft in so far as the individuals peacefully live and dwell together. However, in the Gemeinschaft they remain essentially united in spite of all separating factors, whereas in the Gesselschaft they are essentially separated in spite of all uniting factors (Loomis 1957:197).
Although one interpretation could be of a romantic view of the simple and understandable Gemeinschaft, it seems that Tonnies was under no illusion that such a system would be sustainable. He saw the two as a process, “For him, Gemeinschaft represented the youth, and Gesellschaft the adulthood, of society” (Loomis 1957: 3). As with many social systems, Tonnies says, “the essence of both Gemeinschaft and Gesellschaft is found interwoven in all kinds of associations” (Loomis 1957:249).

A similar concept of community types was introduced by Weber, who referred to the two types described by Tonnies as Communal and Associative. He described the communal relationship as subjective and emotional, and the associative amongst other things as, “rational free market exchange, which constitutes a compromise of opposed but complementary interests” (Parsons 1947:136). For example, market place activity and family activity are opposed in nature, but complementary in the sense that the people are dependent on both. Weber emphasised that it was not sufficient that people have common qualities, a common situation, or common modes of behaviour to form a communal social relationship. He said that “it is only in so far as this relationship involves feelings of belonging together that it is a ‘communal’ relationship” (Parsons 1947:138).

Durkheim, whilst agreeing with Tonnies’ Gemeinschaft, disagreed with Tonnies’ Gesellschaft saying “I believe that the life of large social agglomerations is just as natural as that of small groupings” and “there is a collective activity in our contemporary societies which is just as natural as that of the smaller societies of previous ages” (Giddens 1972: 147). Unlike both Tonnies and Weber, Durkheim endeavoured to understand the process that binds society giving it solidarity. He introduced the notion of ‘collective conscience’ and argued that it is the division of labour that has created two ideal types of society, one characterised by mechanical solidarity and the other by organic solidarity. The society showing mechanical solidarity is cohesive, and has a
high collective conscience, because the people perform similar tasks and consequently there is no division of labour. On the other hand, the society displaying organic solidarity is comprised of people whose labour is specialized which means that the people are bound by their mutual dependence on each other (Ritzer 2000: 78-83).

At a slightly later date, but still in the early 20th century, Robert MacIver conceptualised community to be any physical area where people develop common characteristics and social relationships that distinguish them from other areas. These characteristics MacIver named ‘the common life’. He sees an interconnection between small and larger communities but says “In the infinite series of social relationships which thus arise, we distinguish the nuclei of intenser common life, cities and nations and tribes, and think of them as par excellence communities” (1920:23).

In the mid 20th century, Hillery (1968) points out that early community theorists studied representative communities to arrive at their formulations. Perhaps as a consequence Hillery chose several “case studies” to give further meaning to communities (1968:13). As with MacIver, Hillery saw community as having a tangible presence and based his theory on the ability to meet certain pre-determined common criteria.

There have been many diverse theories of community since those early beginnings, and it is possible that each changed with the advent of new technologies and the consequent shift in the labour market. However, the area that has caught the imagination of many present day sociologists is that surrounding the use of the Internet and the associated virtual communities that have been spawned. Neither Tonnies, Weber or Durkheim could have envisaged the development and use of computers and the Internet that had occurred by the end of the 20th century and the beginning of the 21st century. If they had, their ideas of community may not have required the immediacy of presence. However, I argue that Tonnies’ notion of ‘all kinds of
associations’, Weber’s ‘feelings of belonging,’ and Durkheim’s ‘conscience collective’ are relevant to the social relationships that some hard of hearing people manifest through Internet communication. Indeed, the ‘Hard of Hearing Online Real Community’ that I later describe resonates with aspects of each of these theories.

**Virtual Community**

This paradigm shift in communication techniques, and subsequent community construct probably had its beginnings in the technological revolution of the 1970s and early 1980s. Writing in 1981, Jones suspected that a future using computers would bring social changes, “computerisation is the lead technology of the post-industrial revolution, and will help to create a post-service society marked by unprecedentedly rapid changes in the nature of work, society, communication and personal experience” (Jones 1981:100). By the 1990s words such as ‘net’, ‘virtual’ and ‘cyberspace’ were commonplace, and a new concept of community was emerging. At the start of the 21st century the personal computer had been in existence for approximately twenty years and for much of that time it has been in a constant state of change towards more user-friendly computer and Internet access systems. Similarly, these technological improvements have been in tandem with the birth of the sociological discourse of virtual community.

The term ‘virtual’ implies that whatever the object is that it is describing is incomplete or perhaps not quite real. It would follow then that in the example of community, a virtual community would be one that is not quite a community, or perhaps not quite a real community. Furthermore, a virtual community is based on virtual reality, which “allows the user to experience the sensation of being present in an environment” but it “may never be the same as a social community” Gattiker (2001:14). Conversely, a real
social community will never be the same as a virtual community but “a social community may in part be virtual (e.g., e-mail, fax and telephone)” Gattiker (2001:15).

In his editorial on Internet culture, Porter (1997:xii) ponders “whether what comes out of all this virtual talk can be properly termed ‘community’ is a complicated question.” He does say that these virtual interactions “when sustained, can give rise to a unique and intriguing form of social space, and one that will continue to provoke reassessments of the fundamental nature of community itself ” (1997:xii). Moreover, Porter says “the defining action of Internet culture lies not in the interface between the user and the computer, but rather in that between the user and the collective imagination of the vast virtual audience” (Porter 1997:xiii).

This proliferation of Internet uses can range from the dissemination of public information, through to commercial advertising, to private messages between family and friends. Online support or self-help groups have emerged for many people in a wide range of ways, for example those who find their daily lives are affected either emotionally or by physical impairment and seek information from other people who may be similarly affected. For others, the Internet provides a global space for non-immediate communication between people with a similar interest to exchange knowledge and ideas. Many of these groups share characteristics similar to the early theorist’s definitions of community. Rheingold (1993:5) described Virtual Communities as “social aggregations that emerge from the Net when enough people carry on those public discussions long enough, with sufficient human feeling, to form webs of personal relationships in cyberspace.” This computer-mediated communication is described by Castells (1996: 22) as begetting “a vast array of virtual communities.”

Whatever the form of community, Feenberg and Bakardjieva (2004: 5) say there are five attributes that run through both real and virtual communities. Whilst I describe
these distinctions at this point, I shall give examples of how these help to define the online community that I describe later in the thesis. The “identification with symbols and ritual practices which requires loyalty and respect” is something that all communities aspire to. For a community to function without turmoil the members must accept common rules and to do this they must display self control. Not always readily evident is the need for mutual aid and mutual respect demonstrated by fairness and civility to each other. The fifth point is that of authentic communication between members and groups within a community. Sincerity, truthfulness and tolerance are seen as necessary for this attribute. Although some of the behaviours are probably beyond what the normal person and organisation practices completely, these attributes are seen as the ideal for the continued success and cohesiveness of the community.

Example of an Online Community

The online community that I refer to is called the ‘Say What Club’ (SWC) and has a membership of several hundred people. It was formed in the early 1990s by a few hard of hearing people in the USA but now has members from many European countries, England, South Africa, Malaysia, Jordan, Australia, New Zealand and Mexico. As a consequence, the SWC is divided into groups with manageable membership numbers. Each group has a name; for example I belong to Vistas group. My observations over a 2-year period suggest that many of the members regard the Vistas group as a family, second only to their real families. There are firm on-going relationships formed on Vistas, which leads me to the comparison with Tonnies’ Gemeinschaft community. Furthermore, as some SWC members have physically met, the empathy they show each other when communicating, either by speaking clearly and slowly or in writing, has further elements of Tonnies’ Gemeinshaft. The Say What Club is a legally constituted body with board members, and sub-groups that allow the organisation to function formally. This aspect of the SWC community shows similarities to Tonnies’ Gesellschaft, and contains aspects of Durkheim’s organic solidarity.
The main reason that people usually affiliate in groups either physically or online is because they have a common interest in a hobby, (e.g. growing a rose garden, Gattiker 2001:14), task, purpose or a profession. Internet research suggests that the groups that attract people with specific disabilities wanting information and emotional support tend to be referred to as ‘support groups’. For example in a study of an online group of people with hearing loss, the group is referred to as a support group (Cummings, Sproull & Keisler 2002). Prior to joining the SWC I briefly joined what I believe was this group and it was very apparent that it’s sole mission was to provide support and information for hard of hearing people. On the other hand, together with hearing loss information, the SWC provides its members with an emotionally safe environment in which to socialize. What every member of this community has in common is being, or becoming, isolated from people in their everyday lives. This isolation is the driving force to form ties with others, and from this to explore common interests, on a broad spectrum of topics that would not otherwise be discussed by the members of this group, if it was simply a support group.

I argue that the Say What Club is a unique community because of the nature of its members. They are not communicating with each other initially because of common interests, as theorists generally tend to indicate, but because they have that fundamental need to communicate and connect socially.

This concludes the section of the thesis locating hard of hearing people and their relationship with technology at the start of the 21st century. I have given them a historical position of social isolation and argued that computer technology is now providing them with a more favorable future. In the following chapter I shall discuss the methodology, instruments, and methods of data collection used in this thesis.
Chapter 5:

Research Methodology and Plan

In this chapter I describe the research methods, plan, instruments and aspects associated with online data gathering in developing my thesis. Finally I provide an outline of the data organisation and analysis techniques employed.

Research Methods

Several different methods were used to gather data for this research. Traditional qualitative methods of physical participant observation and physical interviews were combined with the relatively new method of online qualitative research. The online method involved a questionnaire in the form of a survey, participant observation of e-mail conversations and participant’s personal stories transmitted by e-mail.

Research Plan

As the initial stages of the plan involved online contact with the participants I have detailed the processes followed. What became apparent during this initial process was the differing levels of familiarity with the PC technology and resourcefulness in making it work. I have therefore also included an account of each stage including some of the difficulties that I encountered and how these were resolved.

My primary motivation for joining the SWC was to gain information about cochlear implants. After several exchanges by e-mail my connection with the group developed from being purely a source of information to being a legitimate pleasurable medium for social exchange. It was at that point I recognised the site’s research potential. Before formally submitting a research project application to Murdoch University I sent out an exploratory inquiry to the group to determine whether or not there were any volunteers
for a possible research project. Knowing the formal ethical requirements for any research project I also impressed on the group that I had joined the group for cochlear implant information, found I enjoyed their ‘company’, and the idea for research came later. This procedure represented the first stage of the online contact, and from that I received twenty responses from a total of four hundred members.

Having gained approval from the Murdoch University’s Human Research Ethics Committee I e-mailed the twenty prospective participants including as an attachment a consent form for their consideration (Appendix 1). The e-mail requested that if they were still interested they should read the consent form, sign it and e-mail it back to me as an attachment. This complicated and time-consuming procedure is one essential aspect of online research communications, and represents the second stage of the participant contact. Of the original twenty volunteers there were ten replies. In the time delay between my initial inquiry three people had left the group, and five e-mails were returned because the original addresses were no longer valid. Two responses did leave me to conclude that perhaps the completion and return of the consent form proved problematic. These participants said that they could not send the signed form back because they did not have the necessary equipment. Consequently I accepted and took their typed consent via e-mail as official. From these exchanges it is clear that the respondents cannot be assumed to be representative of all such hard of hearing Internet users. Consequently the results of this research are therefore proposed only to be suggestive rather than definitive.

The third stage of the contact was to send the questionnaire / survey as an e-mail attachment requesting completion and return. As with the consent letter, several participants had trouble with the ‘return’ procedure. Unlike the latter however, there were no queries, but a variety of ways of responding. Some responses were downloaded, answered and forwarded back as an attachment. One person retyped
each question and answer directly onto a new e-mail, whilst the remainder sent attachments with numbered responses corresponding to each question.

Having received all the replies to the questionnaire /survey I was ready to develop the fourth stage of the online research. This was to observe and record on-going conversations between the participants in the group. The first obstacle came when attempting to set up a separate address similar to the one I used when communicating with my SWC group. What I thought would be straightforward proved a difficult exercise, and it took the services of the Murdoch University’s IT department to provide a successful outcome. Not all participants could understand my concept, resulting in delays and lack of spontaneity in the few exchanges that did eventuate. As a consequence I decided to abandon that aspect of the research, requesting instead to use the exchanges that they had from time to time with members of the larger group of SWC members. To protect SWC members that had not volunteered for this project, I guaranteed that I would not be using any of their responses, either actual or implied. The final stage of this online process was to ask the participants to give their reasons for their hesitancy in communicating with each other as a small online group. This was done just prior to cancelling the online address that was used for the contacts.

**Instruments**

Four instruments were incorporated into my research. These consisted of:

- online contact developed in five stages, including a questionnaire/survey used in the fourth stage and online conversations as the final stage.

- mine and five participant’s stories as hard of hearing people, our relationship with technologies, and how this has led us to feel connected to an online community.
• participant observation made possible at a conference designed specifically for hard of hearing people, at a convention organised by and for, hard of hearing members of the Say What Club, and observation of online e-mail conversations.
• three physical participant interviews.

The online interviews and conversations, participant observations, and the physical interviews in real time are the three main instruments that allow for some triangulation of the various forms of data with the point of intersection being the union of feminist with traditional sociological research techniques. However, a far more elaborate and extensive research strategy would be required to take this research beyond its suggestive outcomes.

**Questionnaire / Survey** (Appendix 2)

To gain some knowledge of each participant and their relationship to technology I developed the questionnaire / survey around four purposes. The first consisted of four questions, designed not only to get some basic information about each participant, but also to see how these related to the remainder. For example I surmised that the age, when related to either the education and /or occupation of the participant may indicate the extent to which they engage with technology to aid their social relations. The second section centred on their hearing loss, the third concerned their use of technology and their financial situation, and the final section focussed on their relationship with the Say What Club.

**Participant Observations**

The first of these took place over five days at the 7th International Congress of Hard of Hearing People in Helsinki. As the theme of the congress was Accessible Communication it seemed an appropriate site to observe the technologies used that enabled the delegates to hear the lectures and how they communicated with each
other in a noisy environment. It was also an appropriate time to investigate the possible existence of research on any other online hard of hearing communities.

On the same overseas trip I was fortunate to attend the annual convention of the SWC in Minneapolis in the USA. Although well planned and organised this convention was less formal than the Congress and consisted solely of SWC members acting and behaving as a community.

The observations of online conversations between the participants and members of SWC took place over several weeks.

**Aspects of data collecting**

There are two aspects of the data gathering that I will address. These are face to face interviews and online interviews with hard of hearing persons. From previous research in which the participants were interviewed in real time it was clear that there were difficulties not only in verbal communication but also in the physical positioning between hard of hearing participants and a hard of hearing researcher. These two matters need addressing before an interview can commence (Collins 2001). Whilst online interviews may introduce a new set of difficulties involving privacy, prior awareness of these can help. Furthermore, as I use feminist research techniques in my communications with the participants I shall include some reflections on that process.

**Face to face interviews with hard of hearing persons**

In a participant interview where only one person has a hearing loss, it is relatively easy for a researcher and participant to choose a seating position for mutual advantage. However, when both parties have a hearing loss the situation can be complicated depending on which ear, or both ears, and whether they wear hearing aids, and again in which ear, and so on. In one of the interviews in previous research both the
participant and I had a profound loss in both ears, although I could manage better in one ear with a hearing aid than could the participant. We found that we were both comfortable sitting facing each other in very close proximity. This same position would be a cause for concern in an interview between two hearing people, and as I found out later, between a male participant and myself. In the interview, words that were not understood were then spoken slowly and clearly, but not loudly, directly facing the hearing aid, or by occasionally emphasising a letter, or writing down key words that either of us found hard to hear. This same participant had a strong Scottish accent, which at times proved difficult for me to decipher. Hard of hearing people with some lip-reading training are very aware of the mouth movements of others, and accents and/or poorly enunciated words are often difficult to decipher. It is also difficult to lip read a person with a beard or a moustache, even though this may not cover a speaker's mouth. A second participant in this study had an intermittent hearing loss. As I was in effect interviewing a person with normal hearing I chose our seating arrangement to suit myself. A third interview and one that proved the most challenging was with a male participant who had been hard of hearing for 48 years and did not wear a hearing aid. We agreed that the most comfortable position for each of us was at either end of a sofa sitting facing each other. There was a greater physical distance between us than I had experienced when interviewing women, and this proved to be a disadvantage as he was softly spoken and I had to ask him to repeat his responses several times. He also asked me to repeat some of my questions (Collins 2001:28-31).

**Online Participation**

The second aspect of data gathering involved the use of online initial interviews followed by e-mail communication over several weeks between the participants. In recent years there has been a proliferation of online groups and online chat rooms. These may provide opportunities for anything from a vicarious 'peep' at others supposedly private conversations to general information on an infinite variety of topics,
to more specific groups offering social support on a variety of illnesses or conditions. Online communications also have a range of problems, such as spontaneity of speech, the lack of visual cues, misunderstood nuances of the voice in speech, context of the words used and even the credibility of the communicators. Consequently this method may not be best suited for researchers and participants with normal hearing. On the other hand it can allow for a wider international range of participants, it eliminates travel time, the time when interviews can be conducted and is physically secure. However, by using this medium I have eliminated the crucial issue of physical position in face-to-face interaction for hard of hearing people. Furthermore because of the nature of the SWC, and having previously met some of the participants I consider their common desire to advance the knowledge of their hearing loss, their credibility is not an issue that I would question.

Researching online groups has brought up valid concerns of methodological problems. Im and Chee (2004:1) proposed future directions for Internet survey studies “including dealing with ethical issues, getting computer expertise, using emotional strategies, and independent discourse, and using national and international approaches.” These methodological issues are still in evidence today. Whitehead (2007) points out that there has been little research done into how Internet–mediated research should be developed, and found that three key areas are needed to set up Internet –mediated research. These are “addressing sampling biases, ensuring ethical practice, and exploring the validity of data collected using an online interface” (2007:1).

For those who have researched qualitatively online, the Internet is proving to be a rich site for sociological studies. In their study of ethnicities on the Internet Parker and Song (2006:1) found that although collective identities still matter, a new form of interaction developed which had the potential for new forms of social action between ethnic groups and the wider society. Gender differences have been found in two online
studies. Herring (1994) observed “that women and men have different communicative ethics.” More recently Seale, Ziebland and Charteris-Black (2005:1) found that women seek emotional support whereas men tend to seek treatment information when researching the Internet.

It is relatively easy for researchers to gather information by ‘eavesdropping’ the multitude of readily available conversations. However, there are ethical issues to be considered. Reading several of these studies leads me to the conclusion that the Internet is wide open to this form of unethical behaviour. It does appear to be a perfect method of observation whereby the subjects are unaware that they are being scrutinised. This method of observation, is perhaps the online equivalent of participant observation. Whilst some researchers proceed only after gaining permission from online group members, there is evidence that many others do not.

For his research Wright (1999b) requested support from one specific group, and in another study advertised for participants via the bulletin boards of various online support groups (1999b: 1,3). It should be noted at this point that neither of these studies mentioned whether or not the subjects were hard of hearing. However the first study was designed to use a group of senior citizens that, as shown in the demographics mentioned in chapter one, would include several hard of hearing people. A study conducted by Michael Noer (1995) supporting Internet use for the elderly with no mention of hearing impairment, but mentioning benefits for blind people, similarly requested support to proceed. He says “Advances in computer technology, such as mouses, voice recognition software, large-scale type, speaking computers and braille keyboards allow a wide range of users to go on-line with ease” (Noer 1995: 1).

On the other hand, Gallegher, Sproull and Keisler (1998) conducted a study, the wording of which suggests that no prior permission of those observed need be
obtained. They say, “The existence of electronic groups provides an opportunity to unobtrusively observe the dynamics of particular support groups” (1998:2).

The ethics of online studies is becoming an increasingly controversial issue. In the online community of which I am a member, there are several distinct smaller communities. I was aware that in the small Vistas community that I had been communicating with prior to this research, there was one person who held very strong views concerning privacy issues. Not only did this person want protection from ‘lurkers’ but also felt that the Vistas exchanges should be private from the larger SWC community. Other members, who pointed out to her that outsiders could access any online conversation, did not share her concerns. This issue was resolved by agreement between the members that each individual’s private home address and phone number would not be made available to the larger community, but could be shared privately among Vistas members. Another strategy to avoid some online intrusions in the group’s online conversations uses a formal application and registration made through the group’s executive before permission is given to join the group. Even this procedure is not foolproof. Toward Christmas 2003 I wished to send one of the members a greeting card. Having misplaced her address, I searched and found it, with her telephone number, on the ‘white pages’ web site. Today, if a person uses the Internet it is probably impossible to protect one’s privacy. Another example of how a web user’s privacy is compromised occurred recently when I joined an online friendship group recommended by one of the participants of this study. Because this person’s integrity was not questionable, I joined the group out of curiosity. Before she sent a welcoming email, I received one from the principal organisation that assists these groups. Upon opening this mail, to my surprise, I was invited to form a group of Murdoch members, either undergraduates, graduates or alumni. The only connection the organisation had was from my email address, which had Murdoch.edu.au as part of it. This type of online behaviour appears to remove all vestiges of privacy. Even now
that I have withdrawn from the online friendship group, the larger organisation has some of my details.

This valid privacy concern is also demonstrated from Eysenbach and Till’s study of research ethics “particularly concerning informed consent and privacy of research subjects, as the borders between public and private spaces are sometimes blurred” (2001:1). It is worth noting here some of the comments that were encountered in their research. “Why can’t researchers do the ‘hard way’ as they used to …and leave us alone on the Breast-Cancer list?” and one woman was “somewhat hostile, assuming that [the researcher] had behaved voyeuristically, taking advantage of people in distress” and that “the idea of using conversations as data had not occurred to many members” (Eysenbach & Till 2001:3).

Fast approaching a genuine cause for concern is the recent offering of Google Earth. A free download literally allows visual access to many private backyards. Whilst the average Internet user may peek voyeuristically as they can do with many email conversations, the criminal element in communities and unethical commercial organisations may employ more sinister means to access a person’s property. These are genuine reasons for concern, and more pressing, than what the researcher’s curiosity can produce, whether with approval or not from the research body.

**Feminist Techniques**

The adaptation of Smith’s argument could be used for both male and female participants because hearing impairment affects both sexes. However, as the majority of the participants of this study are women, I shall briefly describe some feminist interview techniques that I used. Since the advent of the women’s movement of the 1960’s and 1970’s many feminist scholars have written of their experiences when using women as their research subjects, and it is from several of these that I have drawn my
research understanding and techniques. Feminist sociologist Ann Oakley describes how she discovered a problem when interviewing women. When women asked her questions concerning her experiences in relation to the research topic she felt she had to participate. This ran contrary to the given interview techniques where the interviewer is required to remain ‘objective’ (Oakley 1981: 30-61). From her research into feminist techniques Reinharz (1992:263) has observed that “in those projects that involve interaction with people, feminist researchers frequently express a sense of connection to the actual people studied.” A timely reminder before my interviewing process began came from Acker et al (1983:425) who states that it is important “to minimize the tendency to transform those researched into objects of scrutiny and manipulation.” Starting from the standpoint of women is a common and almost essential part of doing feminist research. Consequently this means that autobiographies and noteworthy events in the author’s life for example, may be considered appropriate research topics. The research techniques suggested by Kirby and McKenna (1989:244) use the term ‘conceptual baggage’, in a non-pejorative sense, to refer to the recording of any reflections and insights that may occur during the interview process. This strategy is designed to show whether or not there are any preconceived ideas that could influence the research questions. At a later date, Oakley suggests “that maintaining the division between ‘quantitative’ and ‘qualitative’ methods and the feminist case against quantification is ultimately unhelpful to the goal of an emancipatory social science” (1998:2).

Smith observes a “problematic of the everyday world which is the disconnected relations of people who live alongside one another in the same locality but whose social relations are organised by social relations external to the local area and not appearing in it” (1987: 94). A parallel to this is the relation of hard of hearing people who lose their hearing in later life after education and work experiences, with the social relations of people who lose their hearing in childhood after learning speech.
Childhood loss can lead to contact with social institutions such as government disability organisations and special education classes. Adult loss can lead to loss of employment and contact with unemployment agencies. They may have a similar impairment but a different social problematic. This difference has further relevance to this research project, as my study involves participants of different ages and from four different countries. Whilst English is the primary language of each, the cultures and ruling organisations differ.

Using Smith’s method of inquiry means locating the participants in their own environment, not making them objects of research “but to be able to explain to them/ourselves the socially organised powers in which their/our lives are embedded and to which their/our activities contribute” (1999: 8). This is particularly relevant to the hard of hearing people in this research who belong to an online community, to organisations that supply the technologies they use, to their work environment, to their country with its various organisations that control their lives and perhaps define them as disabled. An overseas trip gave me the opportunity to meet several of the participants living in North America. As these people had already answered my questions and we had other online communications, I did not intentionally visit to conduct observations or interviews. I went as an Australian tourist accepting their hospitality. However, these exchanges gave me the opportunity to hear some of their stories, and they mine. Starting from our individual standpoints gave me the licence to take advantage of Smith’s concept and record and present their stories.

**Data Organisation and Analysis**

The data for this research were collected from a questionnaire/survey, online conversations, participant observations and participant interviews. Unlike traditional questionnaires the one for this research was conducted online via e-mail. In order to
compare and contrast any thoughts emerging from the answers I found it easier to print hard copies of each set of answers and analyse these on paper rather than on screen. At this stage I allocated pseudonyms in alphabetical order to each participant. These were exchanged in alphabetical order with the real names of each person and selected at random. In other words, for security reasons there is no obvious relationship between a participant’s name and their pseudonym. Unfortunately there was only one male in the group. This meant that his pseudonym and references to the male in the group could be easily traced to its origin by a computer hacker. However, because of the benign nature of the subject matter, it is unlikely that the person’s privacy would be invaded. When it was pointed out that there was a chance that his privacy could be compromised, the participant gave his permission to remain with the research. His reasoning was that he was prepared to assist in any way that may bring an increased public awareness of hard of hearing people.

Whilst it was relatively easy to record questionnaire answers, the use of the ensuing online conversations proved problematic. As previously stated the original concept had been to observe online conversations between the participants. However, setting up an artificial community proved to be devoid of the immediacy of the conversations that I had observed, and was observing, in the general Vistas and SWC daily exchanges. Furthermore, there was a lack of spontaneity in the topics that we discussed. It was at that point that I asked for, and obtained, permission from the participants, to observe their exchanges in the larger online community of SWC’ers. This led to the dilemma of how these exchanges could be recorded, and how the privacy of those people could be maintained, if the conversations were with non-participants. As some of these exchanges were necessary to support my concept of a Hard of Hearing Online Real Community, I described the topic and pasted the participants’ responses and then deleted the conversations. To further protect the privacy of all the people involved, I transferred all of the relevant data to disc.
Just as interviews are normally conducted and recorded in present time, so too are participant observations. Taped recordings of observations can be conducted relatively unobtrusively, but hearing these later can be difficult for a hard of hearing researcher. Because of this I used the age-old technique of writing down my observations. Unfortunately this method can have the disadvantage of visually missing some exchanges. However, I believe that I was able to capture the essence of the various exchanges from body language and the differences between the two different groups of people.

My argument that technology has given hard of hearing people the opportunity to form communities led me to organise the data into categories that reflect some aspects of community. Whilst the research findings are presented in chapter six these categories enabled me to argue favourably in chapter four for a Hard of Hearing Online Real Communities.

The loss of hearing is a complex issue that not only affects the lives of those who are so afflicted, but also the lives of those people with whom they interact. Whilst the separate analysis of the outcomes of these different research instruments cannot in any way be aggregated or their relative value weighed against each other the overall picture presented adds breadth and depth to an understanding of the significance of computer communication to the hard of hearing. In the following chapter I give an in depth account of what one group of hard of hearing people do to function in their hearing communities.

The following chapter gives an in depth account of what one group of hard of hearing people do to function as social beings in their hearing communities.
Chapter 6:

Interview Analysis

Throughout this chapter I will use early sociologist’s theories and Feenberg and Bakardjieva’s (2002:5) five attributes of community as described chapter 4 to locate the SWC as an online community. Furthermore I will give the SWC the added definition of “real” because of the physical meeting of many of its members. After introducing the participants I will analyse the interviews and observations that I have conducted with several of the hard of hearing participants. This is followed with a brief description of how hard of hearing people relate to each other in real time as observed at two gatherings of hard of hearing people. I shall also offer mine and five participant’s stories to reinforce my argument that the start of the 21st century has seen the emergence of a discrete community of hard of hearing people. The chapter will end with examples of several online conversations, including misunderstandings that provide further support for my argument.

In the previous chapter I indicated that the questionnaire /survey was one instrument of this research. I also stated that this was centred on four ideas. With the exception of the initial general statistical description of the participants obtained from the questionnaire /survey I have incorporated the information gathered from the remaining questions into the body of the analysis rather than risk repetition.

1: Participant Description

The participants range in age from within the 20 to 79 year’s age groups and consist of 10 females and 1 male. As previously stated, I received 20 responses to my request for volunteers, but by the time I sent out the consent forms the number had diminished. As the research was conducted online the only criteria necessary was that the
respondents belong to the Say What Club and that they have a hearing loss and that they were not born deaf. Although it may be assumed from previous discussions that only hard of hearing people would be interested in joining the club, this is not strictly correct. There are several deaf members whose parents insisted that they learn verbal speech rather than sign language as their primary language and thus consider themselves to be members of the dominant hearing community. Several hearing parents of deaf, hard of hearing and cochlear implanted children have also joined with the intention of understanding the implications of hearing loss. Hearing partners of hard of hearing members are also welcome; however these couples join a group specifically to discuss their problems and their coping strategies. The hard of hearing partner of a ‘couples group’ must also belong to a group specifically for hard of hearing members.

The hearing parents and partners of hard of hearing members join the SWC for information and support and not for the ongoing social contact that hard of hearing people need. For these people the SWC does act more as a support group rather than the Hard of Hearing Online Real Community that I propose.

It is appropriate at this stage to mention some of the background details of the participants that may indicate reasons for their online communications as a means of social interaction. Nine of the 11 are tertiary educated, and the remainder have attended secondary school. Their occupations are diverse and include three teachers, a dietician who is the former head of a university department, an advocate, shop assistant, psychologist, social worker, chef, bus driver, and an administrative assistant to a state representative in the US Congress. However, of the three participants still in the workforce, one is now self employed and cites his hearing loss as a significant factor in changing from his chosen profession. Another is a social worker working with hard of hearing people, and the third and youngest in the group, is actively seeking
From informal online conversations with several of the retirees, I found that two are self-funded and two have government pensions. The income of the remaining retirees is unknown. Five different nationalities are represented. However whilst the cultures are country specific, with the exception of one person, English is their primary language. There are 2 Australian, 1 Canadian, 1 British citizen, 5 USA citizens and 2 South Africans of which one has Afrikaans as her language of choice. Whilst the implications of the participants’ ethnic origins are not an issue explored in this thesis, I describe the group as white and principally middle class, well educated retired women. Consequently whilst the findings of this study are representative of this group, they may not be so for the general population of hard of hearing people and other groups within it. For example, a study of a hard of hearing population completely reliant on social security for its income, a more heterogeneous mix of people, an indigenous group, a group of male participants, or even a younger group, may have produced different results. From my own experience, the few Australian hard of hearing and cochlear implanted people that I know are elderly and do not appear to be computer literate. However, I do know three elderly hearing people who are computer literate, having learned their skills through local technical school classes. Perhaps hard of hearing people are reluctant to engage in such courses because of their hearing difficulties knowing from past experiences that they will have problems in a class environment.

**Interview Procedure and Observations**

As previously mentioned the interviews were primarily conducted online and done over the space of 2 months and involved four different time zones. Unlike a pre-arranged interview probably taking place at a mutually convenient location, online interviews by e-mail can eliminate the immediacy of both time and place. Furthermore, as the time frame for the research was intermittent over 4 years, I was able to physically meet
three of the participants separately and discuss further aspects of their relationship with technology and in particular their Internet communications and feelings about belonging to the SWC. There is no doubt that the physical meetings with the participants had advantages over our online communications. Even though we had trouble hearing each other, our body language and basic sign language overcame many misunderstandings.

Unlike the participants in my earlier research in real time (Collins 2001), these people were more willing to engage with me, and the meetings were like those of long-lost friends. Perhaps because of our previous online communication we knew of the problems and joys that such contact meant for us. On the other hand it is more probable that this group of people has learned more coping strategies than the earlier group as a result of a greater hearing loss necessitating alternative methods of communication and socialising. We, as hard of hearing people, know that our communication with hearing people can be fraught with embarrassment and misunderstandings. If we sometimes explain that we cannot hear clearly, which in itself disrupts the normal flow of conversation, we may be faced with louder than necessary responses or occasional patronising behaviour, resulting in embarrassment, frustration and eventually alienation.

In our daily face to face interactions we normally employ a set of unspoken rules that allow us to communicate in an easy and uncomplicated manner. We pick up facial expressions and other body language to guide us. We have probably been taught, or intuitively learn, acceptable manners and etiquette so that as little offence as possible is given in the exchange. On the other hand, to communicate through e-mail with people is not so straight forward, as I found out prior to the beginning of my research. The art of online etiquette or ‘netiquette’ is one area of good manners that is foreign to non-users of the Internet and also those, who, like me, jump in for the first time. New
members of SWC are informed of the club’s online etiquette at the time of joining. The club etiquette consists of “no ‘Flaming’ (no rudeness, personal attacks, hostile messages)”. As one member so aptly stated ‘address the topic not the poster’ (Linna 2002: 1). However, a search of the online etiquette sites uncovered a wide range of guidelines on how good manners can be achieved. Much is probably common sense with an emphasis on polite exchanges, but injunctions such as ‘not using all capital letters’ because that denotes shouting and ‘not using all lower case letters’ because that means mumbling, are two common examples that perhaps not everyone is aware of. For those who are aware it is still easy to forget these new manners when typing conversations.

**Interview Description**

The descriptions of forwarding the questionnaires / surveys online and the ways in which each was returned have been dealt with in the previous chapter. I have also stated how I was able to meet three of the participants individually and shall now introduce each in the order in which I met them. These meetings gave each of us the opportunity to informally question and offer suggestions in a non-threatening environment. At this point I shall briefly outline my experiences of these meetings to illustrate some common and some unique points, and to highlight several insights that occurred during the process. To protect the identity of these people I shall refer to them as Alice, Brenda and Clare. As these participants are the first that I write about in this thesis I point out that each participant’s fictional name starts with a consecutive letter of the alphabet and bears no relationship with their real name or initials. For example I will now used names beginning with A, B and C and the next name will begin with D and so on.
Alice’s Interview

Alice, the first person that I met is profoundly deaf and wears a hearing aid behind each ear. Five years ago, after a course of antibiotics, she experienced a rapid and profound hearing loss. Arranging our meeting is worthy of comment, as it was not the normal way for people to communicate for such an event. It is also a method that would not have been possible a few years ago. Prior to the advent of the Internet we would have had to rely on others to make the phone contact, or used ‘snail mail’. Alice does have a voice carry-over phone set-up involving a neutral 3rd person employed to relay the phone messages. However, because of my hearing loss I was not able to use a normal phone, nor was I able to access the telephone voice relay network needed for such communication. I was staying with friends who do not need, and consequently do not have installed, the specialised system. Consequently I used e-mail to contact Alice. This method of communication is not the most reliable for making appointments as there can be a significant time delay between replies which, due to unforeseen circumstances, could frustrate any meeting plans. Although the arrangements for meeting were successful, during the two-hour train journey it took me to meet Alice I wondered whether she would be there to meet me. It was possible that she may not have read my e-mail, as I did not receive confirmation. On the other hand she may have had problems with her Internet connection, which happens to all users from time to time, and thus not received my e-mail. It was also possible that she had replied giving an alternative plan during the time that I was travelling to meet her.

Although I had met Alice on a previous overseas visit, this was the first time that I had visited her by myself and in her home. The first visit had been at a pre-arranged tourist attraction when she acted as a guide. On that occasion I was more interested in site seeing than observing how Alice coped with her hearing loss. That meeting was also very difficult because it was at a time when my hearing had deteriorated to a point
when I could not hear sufficiently even with my powerful hearing aid. I had also
communicated with Alice by e-mail a number of times, as we are both members of the
same SWC group, and I knew something of her history, sense of humour and was
impressed with her ability to cope with her relatively sudden and profound hearing loss.

Since that first visit I have had a cochlear implant, which has greatly improved my level
of hearing. Consequently I was able to hear Alice reasonably well as we walked in
heavy traffic, and later drove to her home. On the other hand I was aware that Alice
could not hear me in either environment so I did not contribute to her conversation
other than to perhaps nod, smile or point quizzically when I needed information. I was
also aware that to attempt to talk to Alice whilst she was driving may have distracted
her. She was a proficient lip-reader and may have taken her eyes off the road to see
what I was saying.

Alice has lived in her busy neighbourhood all her life and before retirement, taught at
the local school. It is probably as a result of this that she feels comfortable and
confident in her surroundings. In my opinion she is what is called ‘streetwise.’
Crossing a very busy street at a junction can be daunting for anyone and for someone
with a profound hearing loss who cannot hear traffic horns, it could be impossible. I am
especially cautious at such times. Alice surprised me by waving her walking stick at
the oncoming fast traffic and then stepping out as it rapidly slowed. My reflex shout to
wait went unheeded as I realised that she could not hear me. She continued walking
and then looked around at me triumphantly saying “I get a lot of mileage out of my grey
hair!” The fact that she could not hear in that environment, even with her hearing aids,
was of no concern to her.

Alice played host in her home and directed me to where she wanted me to sit at her
table before positioning herself to best advantage. Our seating arrangements were
convenient for both of us as we were seated close to each other at a small round table. However, Alice still had problems hearing. Alice goes regularly to speech reading classes, but I put this down to our different accents, mine being Australian and hers what I call broad Brooklyn New York. These accents affect the way we move our mouth when pronouncing words. Furthermore, when I attempted to sit closer to Alice to speak into her hearing aid, as people often do with me, she moved away. From this I concluded that because Alice was a late deafened adult, she was used to keeping the unspoken conventional distance between us that conventional hearing people adopt. This resulted in us using pen and paper when either of us had trouble hearing and comprehending key words. As we were conversing, Alice suddenly ‘heard’ her phone ringing. When asked how she knew this she informed me that she was sitting in full view of the flashing light on her phone. She answered the phone verbally and then waited for a typed message to appear on the screen of the phone. When she had read the message she verbally replied to the relayer who then relayed the message on to the person making the call. The answer was then typed for Alice to read and respond. This process is very time consuming and whilst it allows for a limited degree of freedom it does not have the spontaneity and of a normal phone conversation. Indeed, Alice shared with me that one of her close friends had complained of the system and told her it was too awkward for them to continue their relationship. Alice agreed with her, but said it was the best she could do. When she told me this story she added “let’s face it— it is awkward.” After the phone call and explanations were finished Alice then showed me the lights she had for the doorbell and smoke alarm, and finally her computer, which was situated in her kitchen. As the kitchen is the hub of her house and her light alarms are within easy visibility, it seemed the most convenient and practical place for it. Alice has no family living nearby and has found that many of her friends now find it difficult to meet with her because of her hearing loss. Increasingly she relies on social contact with her daughter and SWC members using e-mail.
Brenda’s Interview

Brenda was the second participant that I visited, and she lived a two-day train journey away from my base. This was our second meeting in as many years and much better organised than our previous one. Brenda’s hearing loss started twenty years ago and now she has a profound loss. She does not wear a hearing aid, and as I cannot reliably use a telephone, we had to make our arrangements via e-mail prior to my leaving. I knew that once on the journey I had no convenient way to contact Brenda to tell her of my arrival time, consequently prior to leaving I checked the Internet site of the train company to determine my ETA at her train station. Although there is now the blackberry communications system that allows people to receive and send e-mails from anywhere there is radio coverage to the blackberry communicator; neither of us owned such a system. We knew from the train station it was a 15-minute ride to her home so that she could then be waiting in the entrance hall to let me in. This step was necessary because of the security of the apartment building where Brenda lived. If Brenda was not waiting in the entrance hall, there was no way for her to know when I arrived. There is an outside intercom on the building, which transmits a message to an appropriate apartment. The person in that apartment can then let the visitor into the main entrance hall. However, in Brenda’s case she cannot hear the buzzer in her apartment, leaving a visitor waiting outside until another resident is using the entrance. This was the situation in my first visit that then entailed the resident who opened the door going to Brenda’s apartment to see if I was expected. Whilst Brenda has a strobe light in her apartment that is activated when her door buzzer is used, the apartment building does not have the same facility connected to the main entrance. On this visit, and with all eventualities covered, I felt confident with this seemingly tenuous arrangement, as I knew Brenda was looking forward to making contact with me and sharing her experiences.
From my knowledge of Brenda I knew that as well as having no hearing she has very limited vision. Her computer is her sole source of meaningful communication as she can use enlarged type to see the messages. She is a very active person taking a daily walk to her shopping centre when the weather permits. However, she is housebound for many weeks in winter when it snows, and it is then that she relies almost exclusively for social contact with SWC members through her personal computer and Internet connection.

It came as a surprise after reading Brenda’s e-mails to hear her voice. Her very quick wit and extraordinary mastery of the written English language, with published poems her testimonial led me to think that she would speak with an English accent. To my amazement I found that she had a very strong German accent, which for me was hard to decipher at times. Consequently she had to occasionally write down difficult words for me. On the other hand I had to write every word for her to ‘hear’ me. Unfortunately this was a very laborious process and did not encourage spontaneity. Neither of us know sign language, but as we ‘talked’ I became aware that I was attempting some rudimentary signs such as thumbs up for OK, nods, joined hands at the side of my head for ‘I’m tired’ and waves for goodnight. Signing is also country specific, so if we could sign we may not have understood one another even though we both speak English. Brenda uses very little lip or speech reading to aid her in understanding others. From my own encounters over the years I know that some people are very adept at this skill, whilst others find it too difficult to acquire. Although Brenda did attend lip-reading classes many years ago I suspect that her failing eyesight, her German language background and her social isolation contribute to her problems.

Although both profoundly deaf, neither Alice nor Brenda has a cochlear implant, so it was with great anticipation that I wanted to meet and interview Clare, a recipient of four years. As with Alice and Brenda our meeting arrangements were made via e-mail.
However, as Clare was also eager to meet me she insisted on being at her train station to greet me. From my previous experiences I was confident that our strategy would work, but Clare was nervous about my travel arrangements. Later she did admit that she was not confident about train travel alone because she could not hear well and felt that her security could be compromised. Perhaps in another time she will become as confident as Alice in her travels and rely on a walking stick and grey hair to get by. However, like me, both Alice and Clare each drive a car and prefer this to public transport.

Clare’s Interview

After meeting Alice and Brenda, who were both in their late 70s and who developed a hearing loss in mature years, it was a surprise to find that Clare and I were the same age and have had a very similar history of hearing loss. In retrospect it seems a pity that I had to travel to America to meet someone with familiar experiences. However, Clare’s experiences with technology far surpass mine. When queried about any ‘assistive listening devices’ that she may possess, she pulled out a large carton with discarded pieces of equipment that she had purchased and tried over the years prior to her cochlear implant. None of this was familiar to me, but Clare knew each piece in detail. Currently she uses a ‘voice carry over’ phone similar to the one that Alice uses. She also uses e-mail to make contact with a number of organisations that she belongs to. However she does not rely on e-mail to the same extent as Alice and Brenda.

Clare’s hearing deteriorated rapidly shortly after completing a teaching degree, putting an end to her nascent career. She could still be an active member of the workforce, but jobs are proving difficult to find. Despite this setback, she has turned to volunteer work and is also actively involved in several online hearing loss action groups. It is she who made me aware of hard of hearing rights and the part it plays in her life. For example, when she was taking me on a walking trip around her city, at the entrance to
a national monument she refused to walk through the security frame that detects metal objects, insisting instead on being frisked by a female officer. She was aware that the rays emitted by the frame could potentially damage the magnets and electrodes in her cochlear implant. From my experience this is not the case, however the manufacturer of her implant had warned of the possibility of potential damage. Clare is one of the Say What Club’s active committee members and regularly attends the club’s annual conventions, travelling by air and staying in hotels organised especially for the event. Prior to our conversations I was unaware that American activists are instrumental in achieving equal opportunities in travel for people with a hearing loss. Air travel is relatively easily accommodated with aircrew being informed; however hotel rooms require strobe lights instead of the standard fire alarms. After one recent air trip she reported to the company management the cabin crew’s lack of courtesy to her, and in return she received a fare refund. Perhaps the larger population of the USA compared with Australia gives hard of hearing people more leverage as consumers.

From our lengthy conversations as part of the Say What Club online community and from our brief meetings in real time, Clare demonstrated her trust in me by insisting that I sit in on an appointment that she had with her audiologist. Cochlear implants are no different from any other form of technology in that they are not perfect and can malfunction from time to time. Clare’s visit to her audiologist was with the expectation that a long-standing intermittent fault in her implant speech processor would be corrected. Her obvious frustration at the audiologist’s inability to find and rectify the fault was felt by me also. I recalled the countless times over the years when I had been in similar situations with hearing aids. Later Clare shared that it was the first time in her experience that she had someone present that fully understood how she felt. Our relative independence by using this cochlear implant technology is limited by the operation of the devices that are in reality only as good as the optimum functioning of the technology and the ability of the technologists to rectify any faults. I suggest that to
say audiologists rely for their work on hard of hearing people is only partly true. They rely on hard of hearing people as a group, but not as individual clients. That point was made very clear when I observed the audiologist glimpsing her watch. No doubt there was another client waiting for a prearranged appointment. The audiologist’s body language suggested to me that she thought Clare was imagining these faults and it was time to conclude the meeting, suggesting finally that perhaps Clare could make another appointment. Understandably there are limitations put on the technologists, perhaps compounded by their inability to fully understand the significance of even minor malfunctions to a hard of hearing person.

Reflections

Reflecting on these three interviews and sharing my own feelings, I found the meeting with Brenda to be the most difficult. The ‘baggage’ that Kirby and McKenna (1989:244) referred to in the previous chapter became very apparent to me as I communicated with Brenda. Because of her profound hearing loss and inability to gain benefit from a hearing aid, she cannot judge how loud her voice is. It seemed to me that she was shouting, and although it may be thought that shouting helps a hard of hearing person to understand what is being said, that is not necessarily the case. A hearing aid or cochlear implant speech processor often distorts loud sounds making them very hard to understand. The ‘baggage’ that I refer to can be explained using Cooley’s notion of a ‘looking-glass self’. For the early twentieth century sociologist C.H. Cooley, the ‘looking-glass self’ consisted of three parts: “First we imagine how we appear to others. Second, we imagine what their judgement of that appearance must be. Third we develop some self-feeling such as pride or mortification as a result of our imagining others’ judgements” (Ritzer 2000:361). Even though Brenda was hard of hearing like me, whenever I am in the presence of another person I imagine that the person sees my hearing loss as a stigma. Although Brenda asked me to tell her if she spoke too loud I did not wish to offend her so said nothing. Consequently I recognised that whilst
I had been given permission to judge Brenda’s loud voice I was caught up in my own baggage and did not guide her the way she asked.

Although all five attributes of community as stated by Feenberg and Bakardjieva (2004) were not evidenced in each interview, there were examples of some of them in each. As I was meeting each person in a non-neutral space, they went through similar social rituals when they welcomed me into their homes. Hugging and looking at each other in close proximity were signs of friendship that may only be reserved for family and close friends. Goffman (1963) points out that space is important when strangers meet. In normal social relations it may take more than one meeting for people to reach a level of friendship where hugs are exchanged. However because of our e-mails and perhaps more importantly our common life experiences centred on our hearing loss, we were able to skip several stages of the rituals that are common in many communities.

In all three interviews I was surprised how open each person was with me. Whilst I had briefly met Alice and Brenda on a previous overseas visit, it was the first time that Clare and I had met. Each one welcomed me like a long-standing friend so much so that we spent long hours talking to each other. We each admitted feeling that we were part of a family. This feeling of belonging was something that none of us had felt since developing our hearing loss. Their openness also confirmed to me what I had suspected from their e-mail conversations. That we respected each other and our dialogues were genuine. Although Alice and Clare have never met Brenda other than online through the SWC, they did join with another SWC member and travelled to South Africa to meet other members. Furthermore their openness with me confirmed what I had suspected from our e-mail conversations. That we respected each other and our dialogues were genuine.
It was very clear to me when reviewing these interviews that of the three participants, both Alice and Brenda relied almost entirely on technology to live reasonably independent lives. Their adapted telephones, doorbells and alarm systems certainly gave them a sense of security, but it was the computer and the connection that it gave them with their SWC friends that provided the greatest social benefit. We had the common bond of our frequent e-mails through the SWC with each other and with the other members of our group. It is because these hard of hearing people have found a mutually compatible communication medium and because at times some of the people physically meet, that I regard the SWC as an example of a Hard of Hearing Online Real Community.

2: Participant Observations

During the five days that the 7th International Congress of Hard of Hearing People (IFHOH) in Helsinki in July 2004 there were three social gatherings at which to observe how hard of hearing people communicate with each other and with the hearing people present. The first of these was a welcome party where it was initially difficult to make verbal contact with other hard of hearing people. The hard of hearing participants attended as representatives of their country’s hard of hearing organisations and as a result tended to interact in their native tongue with their compatriots, although English was the official language of the conference. However, it was probably difficult initially for the hard of hearing people from countries where English was not the spoken language to partially hear and lip-read English spoken with an Australian accent. Consequently my first social contact was with British and Australian delegates, who surprisingly were not hard of hearing, but were audiologists and psychologists. It was at that point that I realised, and subsequently confirmed, that a large proportion of the delegates were not hard of hearing, but professionals whose work depended on hard of hearing people. On further observation of the different groups in conversations it was
evident from the body language which comprised hard of hearing people and which did not. In order that a hard of hearing person may hear in noisy social situations it is necessary to move closer together, even to the point where a speaker shouts into the ear or hearing aid of that person. On the other hand the people who could hear each other tended to place themselves slightly further apart.

A local restaurant was the venue of the second social gathering and was attended almost exclusively by Finnish hard of hearing people and their hard of hearing conference guests. Here the atmosphere was very open and friendly with a great deal of written language used. Each table had notepaper and pens for those who could not hear. The uninhibited way these people behaved was something that I had neither seen nor experienced before. One of the few hearing people present was perhaps slightly embarrassed at the attention our noisy group was creating with passers-by. For the hearing person to note the outsiders probably indicated embarrassment, but for the hard of hearing people it was a great joy to be in unison with others that fully understood what their alienation in a hearing community means. Their behaviour indicated to me that what others thought of them was not significant to them in this context.

Seating at the farewell dinner was not pre-arranged to allow hard of hearing people to sit together. At my table of seven, only two of us were hard of hearing. It was interesting to note our reticence at joining in the general conversation dominated by the hearing people. There was no notepaper available and consequently we attempted conversation mainly with the person on our ‘good side’.

It was apparent from my observations of the participants that by the end of conference there was definitely a separation into hard of hearing and hearing groups. As it is very difficult for hard of hearing people to hear and hence converse in noisy environments it
can turn all but the very persistent hearing person towards other hearing people. Similarly hard of hearing people gravitate towards each other perhaps because they know that writing messages combined with closer proximity to each other is essential to their conversations.

Apart from three other members of the SWC who attended the conference, to my knowledge only one other computer mediated community had members present. These people belonged to a newly formed and rapidly expanding organisation of Finnish hard of hearing people. I would observe that just as ‘virtual’ communities have appeared and flourished only in the last two decades of the twentieth century, the ‘Hard of Hearing Community Online Real Community’ has been an offshoot of these and is still very much in its infancy.

On the same overseas trip I was fortunate to attend the annual convention of the SWC at Minneapolis in the USA. Although well planned and organised, this convention was less formal than the Congress and consisted solely of SWC members acting and behaving as a community. Most people knew each other from e-mailing conversations. However, there was a reluctance to use paper and pens at social gatherings. There could be several and varied reasons for this. One interpretation that occurred to me, a foreigner, was that perhaps the Americans are more discreet than their European counterparts, and their social conditioning over-rides any possible changes to their behaviour. On the other hand the behaviour could be explained by the participants’ personalities. Many foreign delegates at the IFHOH conference were the chosen representatives of their various national hard of hearing organisations. To be a national representative would mean that the person was socially confident and prepared to extensively participate in order to report back to their individual organisations. These people would not be embarrassed to use whatever communication tools were necessary. In contrast, the SWC is a comparatively small
organisation comprised mainly of ordinary hard of hearing people who would perhaps be too self conscious of their impairment to draw attention to themselves, and from force of habit do not shed their learned persona. Of course, as in any community there will be a heterogeneous mix of personalities and the SWC is no exception. Office bearers are probably of a more confident ilk and would be the people to represent SWC at IFHOH conferences.

Both the IFHOH conference and SWC convention made use of technologies to facilitate the delegates’ understanding of the verbal presentations. Communication Access Realtime Translation (CART) technology, which makes use of a real-time interpreter typing the spoken word projected via computer onto a screen. Induction loop systems were available at all venues. However, unlike CART these are only of benefit to those people who have a compatible system in their hearing aid or cochlear implant. These technologies are not new, and are available in several public venues in Australia. CART however depends on the availability of a typist of the speed of the Hansard reporters, and the cost of induction loop installation may depend on either the commitment of the venue owner, or the tenacity of hard of hearing people to ensure that their civil rights are enacted.

Having given a brief insight into some of the public behaviours of hard of hearing people both in groups together and in groups with normal hearing people I now offer mine and several personal stories to broaden the knowledge of what hearing loss means. It shows further that in forming communities by whatever means are available, people satisfy the very basic need to have meaningful social relationships.
3: Personal Stories

The following personal stories not only reflect the need of these representative hard of hearing people to publicise what has been their private histories, but they also show the trust that they have placed in me. Each story displays the individual personality and ways of coping with their hearing loss.

Susan's Story

The start of the 21st century seems an appropriate time to review my past and present experiences and future expectations associated with my hearing loss. I was not born with a hearing loss. I learned to speak and was, and still am, part of that normal world of hearing. Hearing is a taken for granted sense that is not brought into consciousness until it is lost. It was not until puberty when I became aware that I was having difficulty hearing that the loss became an issue.

When I first experienced a hearing loss in the 1950s the local doctor did what had no doubt been a standard treatment for centuries. He cleaned my ear canal. A simple syringe filled with water was used. There was, and I believe still is, a strong belief that the ear canal will clean itself. Poking anything into the canal may damage the eardrum and consequently no great ear cleaning was performed in our house. It was a surprise to see how much debris came out of such a small canal. Of course the problem looked as if it had been remedied and no doubt the doctor thought he had done a good job. A week later I was back in his surgery because the age old non-invasive remedial technology had not worked. That doctor could do nothing else. We parted with the knowledge that my hearing loss was something that usually occurred only in old age, and no mention was made of wearing a hearing aid. Nor was any advice on coping strategies offered. It was 2 years later, as a result of a friend’s chance comment about a relative in the hearing aid industry, that I was introduced to the idea of hearing aid use. Three aspects of this new technology remain in my mind. First, a comparatively
small and discreet device that tucked behind the ear had replaced that bulky piece of hearing equipment. Secondly I cannot remember being upset about the prospect of wearing this modern aid because it gave me communications and social connection with my friends. However, I recall making sure that it was well hidden by my hair specifically so no one would see it. The third aspect was the cost of the hearing aid.

From my recollections of that time, I knew of 2 other people who wore aids. In my view as a child each of these people treated me negatively. It also seemed from the vantage point of youth, that they were very old. One told my parent of a misdemeanour that I had committed, resulting in a thrashing. This misdemeanour concerned the use of bad language between friends in the presence of this person. Because this person wore a very visible body aid we children assumed she was ‘deaf’ and that meant she could not hear us. We had marginalised her because of this unspoken assumption, and her age. Of course I soon learned that hearing aids allow a degree of hearing. The second person was my school principal who rebuked me for addressing her incorrectly. She appeared to be a tyrant with all her students and the very visible body aid, which she wore, added to my assumption that hearing loss was associated with old people. I was embarrassed about wearing the aid not because of the stigma described by Goffman (1963), as mentioned in an earlier chapter, but because of the stigma associated with being old. It seemed that I was a child with an older person’s ailment.

A further reason for wishing to hide my hearing aid came from the audiologist who advised that if it were hidden behind my ear and hair then it would not be visible to others. The implications of this were that if others saw it they would treat me differently. Without question or thought I followed that advice.

The third aspect was the cost of the hearing aid. My parents could see the benefit that it brought me, but couldn’t afford the payment from my father’s low wage. In my
honours thesis I stated that I assumed it was bought with a bank loan at high interest (Collins 2001). Recently I have discovered that my mother borrowed the money from her brother, which he gave unhesitatingly as a gift. Of course there was also the high cost of the batteries, the money for which came from my wages as a part time shop assistant in school holidays and on Saturday mornings. However, without that family support I probably would not have owned a hearing aid until I was in the workforce, and would probably not have achieved a tertiary education. Indeed, I may not have entered the workforce.

In my late adolescence the hearing loss had progressed in both my ears to the point where I needed a more powerful hearing aid. At this time also there was a new development in surgical techniques to correct my type of deafness and because my parents and I were told there was a 99% chance of success I had the surgery. However what appeared on paper to be an ingeniously simple although delicate and precise surgical technique was unsuccessful.

The progression of my hearing loss over the past 45 years has coincidentally paralleled the improvements in the technology used to detect and address the communication prospects of people with hearing loss. As my hearing deteriorated, there was a technological advance in hearing aid development that allowed me to function in the hearing world. As one doctor told me recently, there is no substitute or remedy that will restore hearing to a level where conversation in a crowd, or with background noise, will be effortless; however, these advances that have been made do allow communication that was not possible half a century ago.

With my hearing aid hidden during the day, I was able to participate fully in the hearing world. Each morning I would insert into my ear the ear mould with the hearing aid attached and each night I would remove it. This was done in complete privacy, so
much so that I passed as a normal hearing person. No one suggested that I pass as a normal hearing person. Perhaps it was implied in the audiologist’s sales talk. Perhaps it came from my childhood experience of believing that the neighbour with the body aid would not be able to hear me. It may have even come from my parent’s behaviour whereby they treated me the same as if I could hear normally, and did not mention or talk about my hearing loss or aid. Passing as normal was not a deliberate act on my part but spontaneous. As a result of my experience I suggest that passing as normal is normal for many with an acquired deafness.

Passing as normal was a subject that Goffman (1963) explored as an extension of his work on stigma. He makes the point that where the stigma is invisible to others, then it “is of minor concern in the study of passing” (1963:73). I believe that my passing as normal as a result of my hearing aid helped me socially. However, it probably contributed to my absolute dependence on the aid and an emotional denial of my progressive loss of hearing.

The pattern of buying a new and more powerful technologically advanced hearing aid for my ‘good ear’ became well established from the early 1970’s until the turn of the 21st century. Of course, this pattern was accompanied by an absolute dependence on audiologists. Whilst I have used the term ‘audiologist’ to describe the people who sold me my first hearing aids, they were little more than salespeople trained by different manufacturers to market their product. It was not until the late 1980’s that there was a shift away from these hearing aid sales people to tertiary educated audiologists. These new hearing aid technologists operated independently from the hearing aid manufacturers, measured hearing loss and prescribed the most suitable aid for their client’s condition. For repairs of a faulty hearing aid, the audiologist either employed a technician or would send it to a repair laboratory. The high cost of a hearing aid meant that I usually only owned one at a time. In Perth, Western Australia, this could mean
living without a hearing aid for up to a week whilst the aid was repaired in the Eastern States. These times were very stressful, not only for me but also for my family, because by this time my hearing had deteriorated to a level where my only means of communication was some lip reading and shouting in my ear. Whilst it was brand specific, I believe that the earlier system of the company shop was more focussed on customer service and satisfaction than the present system. Repair technicians were in house and if the aid couldn’t be fixed immediately, the company would lend another.

Economic circumstances allowed me to take advantage of the latest hearing aid technologies. However I could not manage to comfortably hear movies, the words of pop songs on the radio, and many television programmes that I had taken for granted when I was younger. The technology associated with entertainment had increased rapidly during the latter half of the 20th century, but was of no use me. Consequently my young family was not exposed in their early years to a radio in the home. I was dependent on technology but could not enjoy other technologies that our hearing culture takes for granted. Telephones are ubiquitous and it would be rare to find a household in Australia without one. By the end of the 20th century in Australia hearing aids had a switch that allowed users to hear conversations on the ‘phone. Unfortunately, the normal issue ‘phones that were and still are available do not include the advanced technology to adapt the signal to the “T-switch” hearing aid. Fortunately I can now enjoy hearing the TV again as my husband and son installed an induction loop system that is compatible with “T-switch” on my hearing aid.

Over the years of my hearing aid use, my need for it developed into dependence. Managing competently without it in the larger community meant that I had to acknowledge to myself that I could not hear. This dependence was manifested one day when my hearing aid became faulty. Taking it to the technician meant that I had to experience the busy city. As I walked down one of the streets a person stopped and
asked me something. All I experienced was the moving mouth coupled with my fear. Of course I had attended lip reading classes and was reasonably comfortable with that skill. However, very few people can lip read when they have no sound cues. On this day, with no cues, I panicked and ran to the technician who loaned me a replacement aid whilst mine was repaired. This experience did not lead me to an acknowledgment of my deafness. So far as I was concerned I was a hearing person with a slight hearing loss. In the late 1980’s I attended an experiential workshop to perhaps gain some insight into my feelings about my deafness. What transpired was the discovery that I hated my hearing aid and wanted to smash it. Unfortunately the paradox was that I needed it to survive in the hearing world.

Fortunately for my peace of mind and almost forty years since wearing my first hearing aid, I was able to acknowledge publicly that I wore a hearing aid. As a symbol of this I had my hair shaved off to expose my hearing aid. Amazingly I discovered that I was the only one who seemed concerned. The people in the street appeared more preoccupied with their own immediate world than to look at me. A small child did see my aid and queried it. After my explanation was accepted unconditionally I realised that because hearing aids tend to be hidden, children may not be familiar with hearing loss and cannot accommodate it into their understanding.

The start of the 21st century saw a new technology for remedying profound hearing loss. Although I did not appreciate it at the time, the prognosis of a possible cochlear implant has brought sound back into my life. This ground-breaking technology and revolutionary surgery was developed over a number of years in Australia by Professor G. Clarke and his team of research scientists and technicians (Clarke 2000). The technology is often referred to as a ‘bionic ear’ because a major part of it is inserted inside the skull with direct access to the brain. There was a possibility that it would be unsuccessful for me because my auditory nerve and hence my brain had not been
stimulated for forty years. Notwithstanding, I deduced that I had no hearing to lose and much to gain in that ear. Consequently in 2002 I had a cochlear implant on my right ear.

The months following the implant consisted of daily exercises designed to give meaning to the sounds that I was hearing. The first sounds that were processed by my brain reminded me of those of the Australian didgeridoo. Many sounds that I had forgotten were unfamiliar to me. Consequently there was, and still is a questioning as to the origins of unfamiliar sounds. Initially I could not differentiate between male and female voices, hearing on the telephone was non-existent, and music was just a jumble of sounds. Three years since the implant has given me a new lease of life and most of the early indecipherable sounds now have meaning. I now have some use of the telephone and can hear movies in the cinemas fitted with induction loops. Music is still not enjoyable but that is a small price to pay for the gaining of the richness and diversity of the other sounds that most people take for granted. The CI is a speech processor and can not present meaningful music signals to the cochlear and the brain.

Apart from hearing aid and cochlear implant, the other great aid for me has been the development of personal computers and the ability they have through the telephone network to access information and people with similar hearing difficulties. The discovery of others with hearing loss with whom I can now correspond on a daily basis, has opened up my shrinking world and has given me new friends from around the world. Internet banking and shopping for various items now means that I do not have to subject myself to the tiring exercise of hearing. Once again, as with the other technologies, computers cost money, not only for the equipment but also for the user fees to the transmission company.
How we think of ourselves depends on our unique set of experiences, our cultural expectations, and how we interpret these. From the following short personal stories of several participants it can be seen that underlying each story is the need for the extraordinary social contact that the SWC community provides.

Other stories

Having introduced Alice, a USA citizen, earlier in the chapter, she now adds her voice to mine. She mentions the names of several members some of who are also participants in this research. The participants are given a name, whereas to protect the privacy of the non participants, I shall refer to each by a consecutive letter of the alphabet. I have also pasted Alice’s story directly to this chapter to show how typing messages via e-mail can show more spontaneity than formally written letters. Much e-mail may display typing, grammatical or spelling errors and include capitals to represent words, for example SWC. Where an unfamiliar word, jargon or capitalisation does occur I will put my interpretation in bracketed italics. However, I have left the spacing between the words as it was written as I think this may represent a person’s searching for an appropriate word or phrase, or even reflect the typing speed. In my view, these pauses would be seen body language if the people were physically present.

Alice’s Story

I live alone and since my husband died and I have lost more and more hearing, I often don't see or talk to another living soul all day. Nevertheless am never truly alone because of SWC!

It has brightened and opened my world. I have been able to "meet" people of various ages, backgrounds, and intellects. There is usually a prevailing atmosphere of kindness and affection on Vistas. On lonely days, it warms my heart.
Along the way I have found myself sharing joys and sorrows, shedding some tears, and finding some laughter. I have had the opportunity to trade opinions, to enjoy some jokes, -- and to cringe at others!

The people, the very wonderful people, have been a source of support and encouragement. Hopefully, in some instances I could provide some of that for others as well.

In these words Alice shows the reciprocity of mutual aid, which is one of the characteristics of a genuine community.

As a member of SWC, I could get and share information and experiences, especially, but not just about hearing loss. I think, too, that sharing e-mails with such a diverse group has helped me develop empathy, as well as gain some knowledge.

For there to be a sharing of information and experiences it is essential that the information communicated is authentic.

SWC and the people in it have helped to broaden my understanding and ability to cope with the hurdles I encounter on the rocky road to increasing hearing loss (and advanced age as well!).

In addition to Vistas, I've also learned a lot about hearing loss from other people on Explore which is another SWC group predominantly devoted to hearing problems.

Along the way, I think I've developed some humility and tolerance and gained some insights. I've come to see how multi-faceted people are, and that everyone at some time or other has something worthwhile to offer. I think it has helped me develop a more open mind. I've learned to like, respect and sometimes admire some people who originally may have turned me off. We really get to know each other!
I have also been fortunate in making some good supportive friends.

For Alice’s to have ‘good supportive friends’ there must be mutual respect, which is another of Feenberg and Bakardjieva’s (2004) characteristics of community.

After my husband’s death, and my increased loss of hearing, one of the things I missed most was the opportunity to travel. I had just about given up on the idea. Almost like an unexpected gift from a fairy godmother, Doris and Eve invited me to South Africa! I got to take the "trip of a lifetime". I discovered that "Yes I can!!" and spent time with 4 unbelievably wonderful women. This was truly one of the highlights of my life. What a wonderful fringe benefit to losing my hearing!!

There are times when I actively participate in SWC and at times when I become a little overwhelmed with some of life’s daily problems, and need to step back and lurk a little.

But one thing I know---All I have to do is turn on my computer and there is always someone there.

Swc, and the people in it, have become my extended family and a very special part of my life

In her questionnaire Alice says that she is not a member of any other online group. Furthermore, her last sentences affirm the position that the SWC holds in her life.

Another participant, Doris, a South African tells some of her experiences and what SWC means to her. In pasting her words I have left the format as I received it to show that presentation on the Internet, just like ‘talking’ is individualised. Whilst her story is long, and at times appears to be taking a divergent route around her hearing loss, to me as a woman, it is a perfect example of how women can tell their story. It
not only involves their feelings but also cannot be told without reference to their family.

Doris’s Story

You wanted a sort of life story, and I do like to tell my story, so here goes. I think I might always have been a bit hard of hearing. I can recall always having a bit of difficulty with the words of songs, and when I went to riding school, aged 12, I used to bring up the rear end of the string because I was small and rode a small pony. The riding teacher would give some instruction or other and I would say...'beccy pardon?’ This was the cue for the riding teacher to say: 'Doris thinks she didn't hear me, but Doris must learn to listen'. It was benign and in fun, but it got me wondering a little. I certainly never had trouble hearing in class at school, training college or university. I taught all voice range levels, from grade 2 to post-grad and never had difficulty receiving input and answers from my students, so must have been pretty OK...prior to 1974.

OK... come 1974. Doris aged 34. Eri, my youngest, was sort of 10 months old, and there was an unexpected pregnancy. We made love on the beach, unprotected, when we were staying with my parents. I remember the night. Pregnancy resulted. I seemed to bleed almost from three months, and there was little doubt that this was placenta praevia. When I couldn't cope with the bleeding at home or when I needed blood transfusions to top up I would clock into hospital. I'd clock myself out as soon as I could. and often against medical advice. After all, I had two little girls at home, and my own parents were really straining to look after them together with hubby, Joe. I'd say to my most understanding doctor, who NEVER considered recommending an abortion..."What about my two little girls?" and his reply
was standard. 'What about the new life you are carrying?' I compromised between the two sets of commitments and did what I could, God and my parents and my husband being my helpers, but at that stage I never compromised values. Life is life, and in my book you just don't snuff it out. Besides, my new baby was moving and I loved him. I loved my doctor, too, for never making a life-ending suggestion.

Like a vampire, I lived on blood and had donated a sufficient quantity in my well years to be saturated with the stuff for many years. One day, as the doc (NOT my regular one) hooked me up, he was called away to an emergency birth, and I figure he ran and left the pressure of the transfusion on too high. Gee! I felt the capillaries in my face popping and thought I was ready to explode. I called a nurse and asked her to switch me down to a more acceptable level at which I did not have my entire head explode, and she said she had not the authority. Minutes elapsed prior to my threat to pull the whole works and her agreement to terminate that particular transfusion. I figure my poor old hair cells (in the inner ear and essential to sound transmission at the physiological level) took a bombardment.

I was clocked into the hospital for an indefinite period at this time and woke up unable to hear the nurse. So, I think, I became HOH. Seriously to profoundly.

Shortly after this I lost my boy baby. I think I still mourn him, and I would have loved him so much, and I tried so hard to have him live and join our family. At least I had the privacy of delivering him myself, as that whole hospital crew were off finding pediatricians and trolleys to take me to the delivery room, and my boy looked at me, alone as we were, before he went away. I treasure this. He was viable. He was Timothy.
There was really no time to think about the hearing loss for a while. I was thinking about the boy who just did not make it. It was actually hard to communicate with hubby, Joe, about this, so I think I did my own thing, communicating with my two little girls around me, at sunrise, in the garden.... and, can you believe it, I have never asked Joe how HE coped? Surely his own loss of a son must have been devastating? Those long years ago I did not ask him to communicate with me. How dense can you get, and where is the retrieval button?.

I'll go years ahead and how wonderful it was to get in touch with America, and some people especially, but that is a long story of salvation and justification,

In another email Doris continues:

Let me take up the thread and finish off! Round about the time that my hearing loss started I was working from home, taking mainly remedial pupils, and some for counseling. This was because my children were small... but how glad I was that I had 'deviated' from conventional classroom teaching as I could never have gone back to that, with the loss, although it was mild to moderate at first. How I liked the ENT who did the assessment.... He was hard of hearing himself, and both sensible and sensitive, and he advised telling others of the loss and asking for accommodations, so that was the modus operandi from the start. I was very glad to have the little aid which he ordered, and cannot recall being ashamed of this or leaving it in a drawer. It was a friend. It was probably as good as technology was in those days... which probably was not very good.
Shortly after the fitting of the aid I was invited to work at the Durban Schools Psychological Clinic and they accepted me on a part-time basis. We visited children with problems and referred by their teachers in their schools, and saw their parents at the clinic. This was quite hard going, not so much with regard to communicating with the children as this was one-to-one in a quiet environment, but with regard to fitting in in the staff rooms. I had six schools to visit..... six different rooms full of chattering teatime people. Case discussions, too, were difficult. Great accommodations were made at the clinic itself, and I was given a cottage away from the noisy road in which to work. One difficulty was that the staff there was bilingual (English and Afrikaans) and my Afrikaans was rusty and I found I could not 'speech read' as well in that language. People were most accommodating, though. I actually needed to work there as it was an institution accredited as a training centre and I needed to work under supervision, post M.A., for a year in order to be able to register as a psychologist with the Medical and Dental Council.

An invitation came to return to Browns' School, for cerebral palsied and learning disabled children. I had worked here previously and resigned when my second child was due. Wonderful school.... it set up a nursery for my first... but having TWO there I thought to be a bit much. LOL. (laughter on line) Anyway, I thought that working in one school environment, getting to know one group of staff and one set of children would be easier, and it was! The school did become very big, though, which meant the classes were bigger and although I had no subject teaching I did have guidance classes and begun floundering a bit. Had to be agile and get to each child's desk as he participated if I wanted to hear him. Case discussion groups, too, were larger and more
difficult to follow. I'd gone onto a larger and more powerful hearing aid…

an Oticon, I think, but it wasn't keeping pace with the progress of the
hearing loss. And background noise, too, became a real problem. Hyperactive
kids ARE noisy at breaks and in the corridors! So, when I bumped into an old
friend who was teaching at Fulton School for the Deaf and she suggested I
apply for a transfer there, I was all for it, and this went ahead with no
setbacks.

For the first time, I was sort of 'taken under the wing' of audiologists,
and plans were made about my hearing aids and moulds. I learned more about
my audiogram and what it meant, I learned that it was better to have two
aids than one, and I learned about new technology, although in the earlier
stages the digitals had not come on the scene and the analogues were all the
rage. These I tried out but could not adjust to. Digitals only actually came
my way after I retired, but the whole process was seen to by the audiologist
at Fulton, and I am fortunate in that I am treated as a pupil and have my
hearing tested regularly and at no cost, and pay for equipment at the same
rate as the children do, with fewer middlemen. I volunteer services at the
school out of gratitude, and the services are not provided because I
volunteer.

Adjustment to hearing loss? I think that because my loss was mild at first
and I had other things on my mind, I sort of 'grew into hearing loss' and
became gradually prepared for it to worsen as it became progressive. I do
not recall specific stages of adjustment, although I do believe that for a
person who becomes profoundly deaf, these stages are necessary, and that a
person who has help and support while experiencing them is indeed fortunate.

One saving grace in my case I think has been a sense of humour. I have made
some boo-boos when it comes to misinterpretation of speech, and my daughters have been encouraged to laugh with me, when laughing is appropriate. I don’t think that they have ever been overly embarrassed at having an HOH Mom. At one stage we even kept a book.... I think though that I sometimes overdid it, and allowed myself to become too much of a clown. I recall at one stage I had a badly-fitting mould and a squeak. This was at Brown’s School. I can remember being in a hushed audience and having the squeak break out, and getting the giggles. Some defence mechanism!! Remember once, too, after a prize giving, the Chairman of the Board asking for a rousing ovation, and seeing people stand and cheer and clap and joining in. Hm. That was supposed to be the rest of the people cheering the staff! Again, laughter sort of saved the day, though underneath I felt very embarrassed.

I had never, till I came online and visited America, had a hearing impaired friend! Fulton supports Deaf Culture, and there is a Deaf Club in Durban...also a meeting ground and social avenue for the cultural deaf. Among the cultural Deaf I felt as I imagine you must have done, Susan, after your CI, when you wrote and said you had wondered about staying on, as your hearing had improved to such an extent that you were better off than we were! I feel luckier or more fortunate than they are although they would not see it like that. Not condescending. In a way, not good enough, or not qualified enough. I knew of a different 'kind' of deaf person and knew that I was not unique, of course, but had never really made the effort to seek out others of my ilk. The Internet opened up new 'Vistas', and a chat room for HOH and deaf led to meetings, 'aha' responses, and finding out about and joining Say What Club. Meeting members has become a reality and I know that people like these are the ones I would choose to be with when making new
friends. I have been challenged to participate in getting a group of HOH/deaf people going in my area, and although there is much yet to do, and we are in our infancy, it is a beginning.

In sharing some very intimate moments and events in her life, Doris is demonstrating one of the characteristics of our SWC community. Through many e-mail exchanges we came to trust and respect each other. In this example I am the only recipient of her story, but it is one that could be told to all the members who are on the list if they requested and wished to ‘hear’ it.

Doris’s introduction to hearing aid use was different to mine. She was also mature age and her feelings were more positive as shown when she says “it was a friend.” However we do have some very common experiences and one which stands out for me is “I had never, till I came online and visited America, had a hearing impaired friend!”

Unlike Alice, who lost her hearing in later life after a successful career, Doris has shown how a hearing loss at a younger age may still not be a hindrance to opportunities. As Doris was a qualified teacher before her loss, she realised that she must make a career change if she was to remain employable.

In both Alice and Doris’s stories there is a sense of confidence gained from being a member of SWC as their hearing further deteriorated.

Eva’s story has a similar ring to it:

I live in an area where there are no other middle aged hard of hearing/deaf people. There is not even a signing population here. Nobody has heard of CART.
There are no SHHH (Self Help for the Hard of Hearing) groups here, no ALDA (Association of Late Deafened Adults) groups. There just isn't the hard of hearing population here to keep them going!

From the time I was 15 years old, when my hearing loss was discovered, up until I came online in 1996, I was pretty much isolated from other hard of hearing people. I felt like I was alone in the world. I had voluntarily withdrawn from socializing in any way, shape or form due to the stress my hearing loss was causing me. In 1996 I bought a small computer, discovered the Internet, and did find a fact-based hearing loss support group. I was able to get information about cochlear implants, etc, on this list.

Some of the support was positive, some was negative, and the thrust of this group was "The facts only, ma'am. Let's not get into any personal stuff". So I did get some support, in a way, but not the social support I was craving. Then, in December of 2000, a woman on one of my CI (Cochlear Implant) lists told me about SayWhatClub. She said "I think you'll like this better".

Boy, what an understatement! I started out on SWC's CI list, and one of the main lists, and suddenly I realized "Wow, I'm home, I belong here!!". It was a feeling like I hadn't ever experienced before as a hard of hearing adult!!

The internet is the great equalizer for the hard of hearing. Our hearing loss is not only NOT a negative here, it's a positive! It is why we belong here with this wonderful group! I have grown SO MUCH as a person since I became a member of this internet-based group, "SayWhatClub". My confidence level has increased, and I know that there is a place where I belong! I carry this feeling of "belonging" with me when I go out into the hearing world, working in the hearing world. It's such a positive thing for me. Thank you to everyone who was responsible for starting this wonderful group! Thank you to all the people who work to keep it going! Thank you to everyone who has been there for
me, responding in a positive, helpful way to my posts.....this month, last
month, a year ago, two years ago, three years ago! Thank you!!

Feenberg and Bakardjieva’s (2004) mutual aid, mutual respect and authentic
communication, are not demonstrated specifically in Eva’s story. However they
must certainly be present in the SWC otherwise Eva would not be demonstrating its
characteristics with such obvious enthusiasm.

**Fay’s story** was part of a conversation we were having concerning ‘coming out to
hearing loss’

Susan, my thought about Kubler-Ross and her grief stages brings one
thought to my mind. I was never able to reach acceptance (final
stage) as long as my loss was progressive. I was always very
frightened of what was coming. Keep in mind that CI wasn’t really
an option at the point where I found out my loss was progressive
(figured this out in early 20s, there was no such thing as CI
then)......and then when the CIs did come out, they just gave you
sound, not words......It’s taken years for them to get where they
are now. I think if I had known that there would be a CI available
for me at the time when my hearing reached severe to profound level,
I’d not have let it bother me as much as I did.

For me, my hearing loss had to be stable before I could accept it. I
dealt with ongoing depression, sometimes acute sometimes chronic.
I got over the depression finally  (after many years of dealing with
it!) once I got the Nucleus 22 CI. Even though I didn’t hear well
with it, I was able to tell myself I’d gone as low as I could go
hearing-wise, and the depression ended. Also, my bad marriage (to a
man who never could accept my hearing loss and was actually mean about it) ended then also. That may have been a bigger factor in my depression than I had realized.

Now that I have a CI in the other ear that works great and there is new technology coming out for it all the time, I have nothing to be depressed about, thank goodness!!

I think one of the things that brought me closest to "acceptance" of my deafness (I'm not talking depression now, I'm just talking acceptance) was joining Say What Club. Finding others who had the same problem I did made the world of difference in helping me realize that I am not a "defective" person or "less than" because I am deaf!!

It should be mentioned here that when Fay refers to herself as ‘deaf’, in my classification she would mean ‘hard of hearing.’ It is not uncommon for hard of hearing people to refer to themselves as ‘deaf’. It is also important to note after reading the previous four stories that living with a hearing partner may still mean that a hard of hearing person is isolated from other hard of hearing people. Alice, whose husband died after she developed her hearing loss, is probably no less isolated than Fay whose husband left her probably because of the difficulties he encountered in living with a hard of hearing person on a daily basis.

Gloria, the only English participant shares her experiences of living with hearing loss. Her unconventional and very uncomfortable method of cochlear implant surgery illustrates the length to which she was prepared to go in order to regain some level of hearing. She withdrew from the Vista’s list stating that she wanted a
Gloria’s Story

You want to know how I reacted to gradually becoming deaf when I was 60. OK. As I learned I was slightly deaf via turned up TV and family talking so fast and me not hearing, I set about the National Health Service to test me. That took a year after I complained about the NHS being dilatory! I obtained one hearing aid in my right ear and could hear perfectly. WE all rejoiced. Too soon.

A year passed and my hearing was worse. Back to the audiologist and two hearing aids. We all rejoiced.

As the years went by I was occasionally hysterical, screaming and (at) the family to help me to hear. We moved from our house in 1999 to a flat here at Port Solent marina since my husband has a boat (I met him in one!)

Southampton, just nearby, is the British HQ for cochlea implants. Point two is that way back in 1996 I joined the Say What Club (SWC) and liked it very much. An Internet thingy for deafies. That was how it came about. I knew far more about cochlea implants than our General Practitioner and having been told in 1999 that no sort/type of hearing aids was of any use to me since I was completely deaf, I asked for a CI.

This was refused on two counts. 1. The anaesthetist refused to take me on due to my emphysema. 2. Hampshire Health Authorities wouldn’t allow an old lady a CI on the NHS.

Immediately we asked to have it done privately but the first reason
still applied until................that wonderful Mr.Pringle, the Consultant asked me "Can you lie completely still on your back for 3 hours?"

Made me laugh out loud. But I said I could. So I was booked into Southampton General Hospital as a private patient willing to pay £30,000 for a CI using a local anaesthetic (like at the dentist) The Hospital + Mr.Pringle made history this way since neither had done such an operation before. I liked it this way as I could follow what was going on. The Implant has been a complete success. I could hear my husband’s voice again.

The very first thing I did age 60 when I knew I would be deaf (no one has heard of HOH in Great Britain - you are either deaf or you can hear.) I printed out on my computer a mass of coloured papers saying in bold "I AM DEAF" and had what I printed made into badges at a local school that had the machine to do it. No cost. I have always worn my badge- colour to suit my apparel.

I now meet many many persons who wonder at me having this badge because, since they are deaf too but won’t admit it, they are rather shocked at my openness. But how on earth, I say, can you get the help you need daily, if you keep your deafness a secret ?

Personal stories tell much about how people handle their hearing loss. Those cited above also indicate the part that the Internet and SWC in particular, plays in helping to make life enjoyable through social contact. Once again it illustrates that whilst hard of hearing people find coping with hearing loss a challenge, there is still a real desire to talk and share their interests with other people who are experiencing hearing loss. The fourth section of these research findings illustrates several such conversations.
4: Participant Observations of Online Conversations

To further emphasise the nature of this online community I shall record several conversations between members that affirm similarities between the traditional physical communities of people that hearing people know, and a computer mediated real community. Whilst the conversations presented in this section could have been attached as an appendix, I chose to include a sample at this point to emphasise the importance of SWC e-mail communications between its members.

As discussed in chapter 4 and again mentioned at the beginning of this chapter, I shall give examples that relate to Feenberg and Bakardjieva’s (2002:5) five attributes of community. These are-

1. Ritual practices
2. Acceptance of common rules
4. Mutual respect
5. Authentic communication

Furthermore because dissent is often present from time to time in social exchanges I have included an extended example of dissent in order to illustrate what was said and done to seek a resolution.

1. Ritual practices

Perhaps the most common evidence of ritual in online communications is in the practice of salutations. Visible acknowledgment of the presence of others is not possible and so resorting to such phrases and words as ‘dear…’, ‘good morning…’, ‘hi’, ‘hi all’ and so on becomes important. The closure can range from ‘hugs’, ‘blessings’, and ‘take care’ to simply a person’s name. Checking many online
conversations confirms this. However, where a conversation is ongoing between several people, usually no introductory salutations occur.

On Vistas we have a ‘birthday genie’. One member has taken on the task of recording the birthday of each member. Two or three days before a birth date the ‘genie’ sends a birthday message addressed personally to the particular person whose birthday is about to be celebrated, and also to the list, (Appendix 3). Many members then send birthday greetings through the list to the birthday person, whilst others send private greetings. When I first joined the group I sent my greetings through the list perhaps to show others that I was responding. However I now send private greetings, which reduces the e-mail traffic and subsequent cost to the SWC. Whichever method is used, I find from personal experience that receiving many e-mail birthday greetings and several e-cards reinforces a strong sense of belonging to this community.

2. Acceptance of common rules

The SWC is an incorporated organisation and as such has elected representatives and various office bearers. New members are advised of the protocols of online communications and are expected to respect them. As in any community there are rules for the common good that we all learn from an early age, and except for a very small minority of people these present no problem. Online communications are no different, and whilst the intent is understood, some of the terms are unfamiliar for the uninitiated. For example, when I first joined SWC I was welcomed with the following expression ‘no flaming’ which was new to me but not hard to understand. In real community life there are differences of opinion and anger shown both in words and body language such as a frown or a finger pointed to indicate anger or displeasure. These are understood even though perhaps not acceptable. On the other hand, even a minor misused word in an e-mail may cause offence to someone on a
mailing list. Virtual communications without the occasional ‘flame’ means communications must be much more controlled, and as such can lack spontaneity.


This attribute is an ideal and necessary for continued social relationships. It is well displayed in the following example from the SWC community. The background shows Alice to have been offline for a few days and people are becoming concerned. After several attempts to make contact with Alice the conversations followed:

Alice:

"I have been in the hospital and am way behind in mail."

Several members responded to this mail.

C: Don’t worry about catching up on your mail, we will be here waiting for you when you feel more like yourself. We can fill you in then. Please write some more when you feel up to it and let us know what happened to you.

All my best wishes,

D: Sorry to hear you have had a health scare and a hospital stay. I do hope they did some tests, and have found out what is wrong, and can fix it soon.

When Alice was discharged and went back to her home in New York, the following message was posted from a concerned community member from California on the other side of the country:

E: I got this e-mail and was so moved I got up and did some texting 2 a few friends.
Here is a non emergency welfare check number for NYPD it is 718 268 4523. They will go and check her.

I also sent you a private email to your mail with her number, again from my police source friends. Let us know if you hear anything. Hugs,

Finally Alice made contact. I have left her e-mail as it was received, and it is not hard to see when reading it that her words and sentences are kept to a bare minimum.

Alice:

home from the hospital. trying to get some homecare. had a small stroke. am a survivor. hard to write much. appreciate all the good wishes and notes of concern. will write when I can. right now a little at loose ends. My family is aware, but no one close by.

Although Alice went off line for several more days, many 'get well' messages were posted, of which the following is an example:

F: Dear Dear Alice

Do take it easy and take care. Sorry to hear about the stroke. I'm glad you are back home and do hope you continue to recover completely.

It is good to see you posting. Do keep up your spirits and take your time. We are all here for you if you need anything.

Love and hugs,
4. Mutual respect

Acceptance of common rules does not always entail respecting the rights and intentions of other community members. However, for harmonious relationships to continue disagreements must be resolved, and not always by the individuals concerned but by other members acting as mediators. It is courteous and common practice for members to acknowledge other member’s posts with greetings, best wishes or commiserations when they inform the group that they are sick, going into hospital, birthdays and numerous personal events that may occur in their life. The following occurred when I rejoined the community after several months’ absence, and observed that no one responded to a member’s fears about upcoming ear surgery. There also seemed to be fewer members and the mood seemed different to my previous time. The exchanges involved myself, some of the research participants and other community members who, whilst not participants gave permission for their conversations to be quoted. Once again where the conversation does not involve a participant, consecutive alphabet letters are used to retain their anonymity.

Hi Susan,

OUCH.......on your other comment! I cannot speck for others here  but........
we are not just a USA based group. As I recall, we talk to …often,
. I for one have given much interest to others, their lives, their interest, AND know others here contribute a lot to this as well. I am not sure what happen here, but I hope
you reconsider your stance on us, and see us as the supportive, caring,
loving, family that we are.

Many hugs, G.
Susan:

There is certainly no need for the OUCH as I am definately not criticising, but wondering whether it is a cultural thing. The main purpose of my mail was to wonder where all the many new people have gone. There are lurkers, but that many on vistas seems a lot.

H: If you miss those you mentioned in your other email then I suggest perhaps you contact them off list and ask them why they are not posting. This is a very caring group of people and I feel bad that you feel as though we are not doing a good job.

Regards,

I: I think your conclusion that we did not respond on the list to....because she was not from the US is really harsh, as well as unfounded. It is unfortunate that SWC does not have archives as does Yahoo and some other lists. I would certainly go into them to look for any hint that what you say is true. I don't believe it is. The only insight into your accusation one way or another will have to come from those Vistans who live outside of the US. I would certainly invite them to write to the list or to me personally, to express their feelings about this situation. If there is any merit at all in your startling criticism, I believe this list will want to take action to see that it is straightened out.

One member was not offended nor considered any cultural slur:

J: Just look out. With a question like that you will be inundated with mail.

If I may? What kept you so busy for a whole year?

No I was not referring to anything that sounded angry towards us Yanks. I was refering to the comment of 'where is every one.'
At this point there were many members adding their thoughts.

K: Susan raises an interesting question about our differing cultures. One of the many reasons why reading the posts on this list is so engaging is because of our diversity. I don't know much about geography, but belonging to SWC-Vistas is giving me a sense of how seasons and time zones differ around the world. Like Susan, I've started inferring cultural distinctions. Perhaps in the USA some of us have become a bit stand-offish. I certainly hope this is not a list for just one country! Diversity is valued.

L: Actually, the questions Susan has asked and her insight in some areas. I felt it was good she asked and share. This gives all of us an opportunity to see what could be seen by a new member, and where we may lack a bit as far as insight.

Vistas is a list that is close but at times need to try and remember that we are of many cultures, way of life, and upbringing in growing up are different too. Questions and comments, such as Susan has posted, can be a way for each of us to look at our self and see where we can be better as a member of Vistas and SWC.

Alice:

Susan, I don't know whether you are still getting Vistas mail. I am forwarding my post on to you, just in case you have already flown the nest and aren't getting Vistas mail, or should I perhaps say flown the brier patch. As you can see, I've already sent it to and Vistas.

Do let me know how things stand with you. Hugs
Although I feel ‘I’ and ‘M’ have done a great job as co reps, and hope they will continue to do so, I strongly feel that suggesting that Susan leave Vistas was premature and uncalled for. Just because someone persistently makes suggestions that do not agree with what we have done in the past should not make us angry. I, for one, do not necessarily agree with some of Susan’s suggestions and was going to give my reasons for doing so, if and when they were considered. Nevertheless, I think her suggestions and comments were thought provoking and showed that she wanted to be an active member. I think her motives were purely constructive. Perhaps I am remiss in not having spoken up sooner.

Inferring that either she agree with the status quo, shape up or leave, kind of leaves her no alternative but to go. I think in her place, I would react in the same way. Surely, we have room for disagreement, suggestion and dissent. Otherwise we will stagnate and become inbred.

Sometimes things are said in haste that really aren’t meant the way they sound. We all have our bad days. Perhaps it’s time for hugs and apologies, or at least to back off and cool down.

M: I don’t post that often, but frankly I must agree with Alice here. I am glad to see you posting again Alice and I wish you good health now and in the coming year.

I have grown to respect everyone’s opinion and we certainly have opinions to share. Such opinions are, in the long run, for the betterment of the organization. I would hope, that SWC and its groups revisit their policies and procedures to update as needed.

Susan has very constructive points of view and frankly is opinioned, as Alice and I can be, as well. I would not hesitate to voice my opinion, and if not agreed with, then respect my right to state an opinion although contrary to yours.
I believe list reps. should refer to the website for us to read the regs., but I don't believe they should criticize a person's right to a contrary opinion, rather than deal with the comments stated. This indicates to me a disregard for the comments and a lack of understanding of them. Ask for a clarification, but don't say a person presents too many negative opinions and maybe they should go off the list and onto, say "Global", which is not even functioning now. This, to me, is a form of censorship of that person, and this effects each and every one of us. Whether ..... humor or the "Tea talk" about health, recipes and weather, this is all-important and no comments should be censored. Frankly, the "delete" button is my friend and time saver!

This is how I envision Vistas, and I'm a "re-newbie". What say the rest of you?

Thanks Alice for your bluntness. I respect all of you for your comments, regardless of source and geographic location. Vistas is for the world and I want to read everyone’s opinions from all over this turbulent planet.

Bear Hugs (gentle, now), Susan, I’m so glad that you joined this group & that you are still here. As you

alluded, the lack of body language when using e-mails is a big factor in misunderstandings, and probably a larger dynamic than differing cultures.

Your questions have been provocative. Like you, I found no hint of criticism in anything you wrote, but perhaps that is because I have no particular stake here.

As shown by the above conversations, resolution of the misunderstanding was a tiresome and lengthy process with these being only a few examples of the many emails sent and received. It is possible that if such a misunderstanding occurred in a face-to-face community where facial expressions, tone of voice and body language are readily seen it might have been resolved more quickly. Such is the pedantic nature of computer mediated communication, but it is well worth persisting
with because all of us believe that we, as hard of hearing people, have a genuine need to respect each other in order to maintain our community.

5. Authentic communication.

Anyone reading the above exchanges will see the genuineness of the conversations. As pointed out in an earlier chapter, the SWC consists of people drawn together because of their fundamental need to communicate with people who understand what they feel because of their hearing impairment. Our topics are usually spontaneous and far reaching in nature. A cursory glance shows the posts to be many and varied as human nature itself. Personal greetings for birthdays, jokes where we get to see the punch line, politics, religion, cultural differences, food, drainpipes and roof plumbing repairs, are just a few of the topics discussed. Even the weather gets mentioned from time to time. Not everyone continually participates and of course for those with a need for an immediate presence albeit computer mediated, there are the bi-weekly chat rooms.

The personal stories presented in this chapter provide a rich source of information about the thoughts, feelings and coping strategies of several hard of hearing people. Each would have joined the SWC looking for help for their hearing loss, and stayed when they found what they had lost. A non-threatening place to socialise and communicate. Most of us have learned from birth to be part of the hearing community. However to be part of a non face-to-face computer mediated community required a refinement of those skills. The general behaviours of the larger community have to be adapted for the computer environment. We cannot rely on the immediacy and multitude of visual clues as to the precise meaning of the online communication. Consequently there are, and will continue to be inevitable exchanges which are misunderstood. However because of the nature of e-mail lists, all the members can witness any dissension and some will most likely offer an
alternative view to prevent an escalation in conflict. Notwithstanding, the stories and
dialogues that I have presented are examples of the caring concern that the hard of
hearing members show for each other. A medium is needed if such concern is to be
communicated and for those who are hard of hearing, computer based
communication provides such a medium in the current absence of any other.
Chapter 7:

Conclusion

As a result of the research conducted in the process of completing this thesis I have come to the view that the technology which is having the greatest impact upon the social lives of some hard of hearing people is not a technology specifically designed and produced for their use such as hearing aids or cochlear implants. The technology that is having the greatest impact is the personal computer through its provision of Internet communication. Whilst the research sample was small and the results can only be suggestive rather than definitive, there is the prospect of greater numbers of hard of hearing people accessing the Internet for social contact.

Early in the thesis I stated that the exclusion of hard of hearing people from general history and the sociological discourse of disability in particular, had similarities to Smith’s (1987) thesis that women had been written out of, or not written into sociology theory. With very little evidence to the contrary I found this to be true, and further that any knowledge of hard of hearing people and their lived experiences has been generated mainly by these people. It was with that in mind, and following Oakley (1981), that I included the personal stories of several of the participants to show how these experiences have affected their lives. In the same chapter I incorporated many e-mail conversations between the participants and other anonymous members of the SWC to supplement the argument as it pertains to aspects of community. Some of these conversations may appear inconsequential and overly laboured to a person who does not have a hearing loss. However, it has to be remembered that many people on the SWC list read the e-mails at different times and perhaps respond from their own viewpoint. Unlike daily physical verbal exchanges between members of a group where some comments may not be heard or are overridden by another person’s, all the e-mail
exchanges are seen. Consequently, instead of only offering comments about conversations, I have included whole sections of them in the main body of the thesis. To relegate them to the appendix would deny hard of hearing people the right to be heard.

I argue that the key reason for the exclusion of hard of hearing people from historical discourse centres on the differing understandings of the term deaf. Generally, the term deaf is taken to refer to lack of hearing. Consequently anyone born with no hearing, or losing hearing later in life, and before the advent of specific technological aids, was considered to be deaf. Moreover I believe that this historical view is still perpetuated today in the general population. However, in reality there is a very distinct difference between these two groups. Verbal language is the key and for deaf people learning to speak in the predominant language of their culture it is extremely difficult. Most of these people learn sign language, form groups and in recent years many claim association with what they refer to as the Deaf Culture. The stigma that they may feel when in the broader community is probably diminished because the other community members esteem them. On the other hand for hard of hearing people the spoken word is the main medium for communicating with others and their loss of hearing tends to cause feelings of isolation. Higgins (1980) claimed that hard of hearing people are not usually members of groups of people with a similar hearing loss who could reinforce positive emotional feelings. Any physical community to which they may belong may not provide the same degree of social support through verbal language that deaf people feel when communicating with each other using sign language.

It is true that at the start of the 21st century various technologies are enabling hard of hearing people to live their lives more confidently than at any other time in their history. Specific assistive technologies, such as hearing aids and cochlear implants, provide a bridge back to the hearing world of oral communication to which hard of hearing people
belong. Other technologies, such as strobe lights for example, have been adapted to give a visual indication of a ringing doorbell. Telephone use can prove more problematic as a strobe light to indicate ringing may have to be connected to a TTY phone if the hard of hearing person cannot manage with an ordinary telephone. These technologies can give a sense of security, which allows hard of hearing people to live independent lives. However, they may not give the hard of hearing person the true sense of belonging to the hearing community. Missed sounds in conversations can result in different meanings being assigned to conversation topics. The outcome of which may leave the hard of hearing person not only frustrated and embarrassed but also socially isolated.

As previously stated, Goffman (1963) connects stigma with being deaf, and also I would suggest with all people with a hearing loss. I also stated that Kochkin’s (1993) study found a definite correlation between stigma and hearing aid use. At the time of Goffman’s claim, a person with a hearing loss and who wore a hearing aid may have had an obvious cord connecting the large battery to their aid piece. This would have obviously signified their hearing loss. At the start of the 21st century, there is a paradox concerning the stigma connected with hearing loss. Hearing aid technology had advanced beyond the need for a visible cord, but music technology has advanced to the stage where many people now wear a visible cord or earpiece for their ipod. No one connects the ubiquitous ipod, nor the mobile/cell phone earpiece with stigma. Consequently in the near future any stigma of hearing loss/ hearing aid use could disappear and consequently it is likely that hearing aid use will be viewed less negatively by hard of hearing and deaf people.

The Disability Movement was one of many movements pushing for social change in the fourth quarter of the 20th century, and it is this that gave both hard of hearing and deaf people the motivation to lobby for equal recognition by the broader community.
However, the outcome of this action appears to vary between countries. Australian hard of hearing and deaf groups have fought for, and to some degree received, equity for affected people in such areas as captioned TV programs, TTY access in public buildings, and induction loops in some cinemas for example. Furthermore these facilities are provided at a relatively small cost for the user. From my observations of several hard of hearing people in the USA, there appears to be a greater access to technological aids than in Australia. For example I had not seen nor heard of strobe lights being used as a doorbell warning, and for many years I was only vaguely familiar with the use of the t-switch/induction loop technology. Notwithstanding the different population size between Australia and the USA, there are clearly different community expectations and outlooks between these two countries. These different reactions no doubt fuel and are fuelled by the direction that the social changes of the Disability Movement continue to take.

In reviewing the medical and social models theorised by some disability theorists, and bearing in mind the high cost of assistive devices for hard of hearing people, I have cautiously proposed an economic model as a suitable site for a proposed hard of hearing discourse. As I have mentioned in Chapter 3, in industrialised nations forms of assistive technology are not universally available, as the cost has to be borne either by individuals, the state, or private health insurance companies. In so-called ‘third world’ countries such aids are far less readily available. Hence in all societies the economics or the finance for the widespread distribution of such technologies is necessarily at the point of intersection of the medical and social models.

As previously stated, the medical model of disability focuses on the disability as an illness and consequently as something that may be cured. If this cannot be done, then it may be possible to remedy the loss with the help of technology. For those hard of hearing people who rely on medical professionals for help, they will probably find that
neither surgery nor hearing aids will return their hearing to previous levels. However, this is not necessarily the fault of the professionals, but may be that result of over optimistic expectations of the affected person. We occasionally see media reports of the outstanding results achieved in medical research, surgery and technological devices. This may lead to the general belief that whatever it is that adversely affects our bodies can be remedied. Unfortunately medical professionals cannot always achieve such outcomes. However they can learn to act towards their client in such a way as to be treating the person as a whole and not just focusing upon their symptoms. A case in point is the example that I gave in chapter 6 when accompanying Clare to visit her audiologist. It became apparent to me that Clare was frustrated when the audiologist couldn’t effectively reprogram Clare’s speech processor. Instead of looking at her clock and then suggesting another appointment, perhaps the audiologist could have empathised with Clare and offered to contact the appropriate company to arrange a replacement until the speech processor could be analysed and repaired. Unfortunately many professionals are overworked and may not have the time to consider other options for the client. Perhaps the manufacturer should be at the forefront in providing greater customer service.

Unlike the medical model, the social model of disability formulated by early theorists would have been a direct result of the Disability Movement’s pressure on governments to give disabled people equitable access to the services that are available to the general population. It was an alternative way of approaching disability and argued that not all disabilities can be treated as an illness. Notwithstanding, just as I have proposed a location for an economic model of disability, hearing loss also falls at the intersection of both models.

The equity analysis that Bush (1983:164) formulates in her alternative view of technology can be incorporated into the social model of disability in relation to hearing
loss issues. When we look at the cultural context of her analysis one of the criteria to be addressed is the organisation of communities. She may have envisaged technologies connected with electricity generation, transport and food production for example in the organisation of a community of locality. However, computer and Internet technology in community formation could equally well be considered as an equity issue when referring to the social model of disability theory.

When I was researching cochlear implant information on the Internet I discovered the Say What Club (SWC). It was not long before I joined this unique group of people and started on a journey of daily conversations on a variety of subjects interspersed with general chit-chat. For the first time in over forty years I felt that I was ‘talking’ even though it was by e-mail with people who understood how hard of hearing people feel about their social isolation. Although the SWC provides members with information, emotional support and social contact, not all members require all three. Many hard of hearing people find the Internet site when they are first diagnosed with hearing loss. Some of these people stay with the group. However my research shows that the people who stay, and contribute the most are those with a long term hearing loss. These hard of hearing people have probably survived years of social isolation and like me, are rejoicing in the new friendships that the club provides. I reiterate that my conclusions are only specific for this small group of people and may not represent the large number of hard of hearing people, however comments from two of the participants demonstrate the feelings I share:

Alice: “SWC and the people in it, have become my extended family and a very special part of my life.”

Eva: “I started out on the SWC’s CI list, and one of the main lists, and suddenly I realized “Wow, I’m home, I belong here!!” It was a feeling like I hadn’t ever experienced before as a hard of hearing adult.”
One factor that contributes to this feeling of belonging is the global nature of the SWC. It means that there is always someone online 24 hours per day 7 days per week and it is this instant communication, although not face to face in physical space, that leads me to view the SWC as a unique form of online community. A Finnish contact did inform me of a similar group operating in Finland, but unlike the SWC members who must use English, that group is restricted to those hard of hearing people who speak Finnish. Furthermore whilst there are other groups for hard of hearing people on the Internet, these appear to be solely for information sharing and as such do not provide the social connection that is essential for a healthy life.

The Hard of Hearing Online Real Community has similarities to the concept of community proposed by Tonnies in the late 19th century, and other prominent sociologists throughout the 20th century. In chapter 6 I have given examples drawn from my conversations with the participants and observations of various SWC conversations that confirm Feenberg and Bakardjieva's (2002) five attributes of community. Furthermore, I found that the concept of virtual community as defined by Rheingold (1993) and later elaborated on by Castells (1996) describes the SWC to some degree. However, the SWC is not just a community formed to exchange ideas about a common interest or hobby, or to play games for example, it was formed to provide a non-threatening environment for communication between hard of hearing people. Because communication per se is the defining factor of the SWC I have set it apart from other virtual computer mediated communities by giving it the classification of Hard of Hearing Online Real Community.

Many years ago I was not optimistic about a possible ‘cure’ for hearing loss. However, with the amazing advances in technologies that we are witnessing at this time in our history, it is possible that the 21st century will see a dramatic decrease in hearing loss as a disability. At the present time Universal Newborn Hearing Screening and cochlear
implants are reducing the potential membership of the significant Deaf community, whilst computer and Internet technology are providing access to social communication for a Hard of Hearing Community. However, gene, stem cell and other biomedical breakthroughs are pointing to a future where people will confidently be free from the prospect of hearing loss and be finally free to be called hearing. Nevertheless the core finding of this thesis is that in the meantime computer-facilitated communication is likely to play an increasingly important role.
Appendix 1.

Division of Social Sciences, Humanities and Education

School: Social Enquiry


I am a Master of Philosophy student at Murdoch University in Western Australia, exploring some of the social issues experienced by people with hearing loss. The purpose of this study is to determine what technologies are available to postlingually deaf people to aid communication; how they discovered these; what costs both personal and financial were needed; what use they have made of them; how have their lives been changed as a result.

You can help in this study by consenting to complete a brief questionnaire, telling your story with special attention to your experiences before and after technological intervention, and participating in online conversations with other participants. Questionnaire and story details will not be available to the other participants without your prior consent. The period for each participant will vary depending on the extent to which they commit to online conversations. It is anticipated that the study will run for 3 months. Participants can decide to withdraw their consent at any time. All information given during the survey is confidential and no names or other information that might identify you will be used in any publication arising from the research.

If you are willing to participate in this study, could you please complete the details below. If you have any questions about this project please feel free to contact either myself, Susan Collins, on smcollin@central.murdoch.edu.au or my supervisor, Dr Michael Campion, on campion@central.murdoch.edu.au

My supervisor and I are happy to discuss with you any concerns you may have on how this study has been conducted, or alternatively you can contact Murdoch University’s Human Research Ethics Committee at, URL: http://www.research.murdoch.edu.au/ethics/hrec/hrec.asp

I (  ) have read the information above. Any questions I have asked have been answered to my satisfaction. I agree to take part in this activity, however, I know that I can change my mind and stop at any time

I understand that all information provided is treated as confidential and will not be released by the investigator unless required to do so by law.

I agree that research data gathered for this study may be published provided my name or other information, which might identify me, is not used.

Participant:
Date:

Investigator: Name:
Date:
Appendix 2.

INITIAL QUESTIONNAIRE

1. Age Range:
   - 20 – 29
   - 30 – 39
   - 40 – 49
   - 50 – 59
   - 60 – 69
   - 70 – 79

2. Sex:
   - Female
   - Male

3. Education:
   - primary
   - high
   - tertiary

4. Occupation:
   - past
   - present
   - retired

5. Age when first experienced hearing loss.


7. Please describe any surgery that you have had concerned with improving your hearing.

8. Please describe any assistive listening devices that you use, such as hearing aid, infra red or auditory loop, special phone, alarms.

9. Does your financial situation allow you to purchase any device that might help you hear effectively?

10. What is your most frequent communication situation?

11. How did you discover Say What Club?

12. List other online clubs of which you are a member.

13. List any other groups or clubs that you belong to in your community.

14. Describe other situations where you use e-mail, for example, ‘talking’ to friends.

15. How long have you been a member of SWC?

16. Why did you join SWC?

17. If you have met any other members, describe how you related and communicated.

18. How has SWC helped in your life?
Appendix 3.

Subject: [SWC-V] Birthday Time again for xxxxx and xxxx
To: SWCVISTAS@HOME.EASE.LSOFT.COM

Hi Folks with all that has been going on I almost slipped up, but I caught myself.
We have two birthday to celebrate. First is our very own xxxxx this coming Sunday the 20 and xxxx I want to wish you a very, very happy Birthday. If xxxx is late with a poem it is my fault because I did not give her the names of the birthday for this month, it totally slipped my mind.
Then on Monday the 21st we have Geri celebrating her birthday, so we need a nice big cake and here it is.

Between the two of you I hope you can blow out those candles and enjoy.

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Happy Birthday from the Birthday Jeanie aka Penny Penguin
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